ADVOCACY IN PSYCHIATRIC HOSPITALS

Evaluation of the Psychiatric Patient Advocate Office

Evaluation Prepared by: Centre for Research and Education in Human Services	Evaluation Committee for the Psychiatric Patient Advocate Office
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EVALUATION COMMITTEE for the PSYCHIATRIC PATIENT ADVOCATE OFFICE

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December 2, 1987

The Honourable Elinor Caplan
Minister of Health
10th Floor
Hepburn Block
Queen's Park
Toronto, Ontario
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Dear Madam Minister:

In fulfilment of the terms of our appointment, we are delivering to you the evaluation report of the Psychiatric Patient Advocate Office prepared by the Centre for Research and Education in Human Services.

We are also delivering to you our Committee's report on the process of this evaluation, its recommendations and their future implementation.

Yours respectfully,

Allan Manson
Chairperson

Evaluation Committee
for the
Psychiatric Patient Advocate Office

Chairperson

Professor Allan Manson

Members

Ms. Sue Campbell
Ms. Pat Capponi
Mr. James Clancy
Mr. Brian Davidson
Mr. Derek Day
Ms. Ruth Gallop
Professor Brian Mazer
Ms. Carla McKague
Dr. Don Wasylenki

Ex Officio Members

Ms. Debi Mauro
Dr. Tyrone Turner
Ms. Mary Beth Valentine

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REPORT
OF THE
EVALUATION COMMITTEE
FOR THE
PSYCHIATRIC PATIENT ADVOCATE OFFICE

The Evaluation Committee was appointed by the Minister of Health in the spring of 1986 to oversee the conduct and management of a comprehensive evaluation of the Psychiatric Patient Advocate Office. Its members were nominated by the various constituencies which play major roles in the delivery of mental health care in Ontario (see Appendix 1). Given the experience and expertise of the Committee members, from the outset they played an active role in structuring and steering this project. Now that the evaluation has been completed, it is appropriate for the Committee to provide you with its report on the process and results of the evaluation.

TERMS OF REFERENCE

The Committee's Terms of Reference were:

1) To examine the structure, mandate and processes of the Psychiatric Patient Advocate Office;

2) To evaluate the quality and extent of services provided and their impact on patient/clients and their families;

3) To assess the consequential impact on the mental health care delivery system and other relevant systems in Ontario;

4) To consider the future of the Psychiatric Patient Advocate Office and psychiatric patient advocacy in Ontario.

From this framework, the Committee focussed its attention on six key issues:

- Effectiveness
- Structure
- Impact
- Organization
- Resources
- Future Directions

The nature of the evaluation, and the scope of these key issues, were set out in a Request for Proposals which was disseminated through advertisements and direct distribution to the research and consulting community. Ultimately, the Committee received twenty-three proposals for this project.

The proposal which exhibited the most comprehensive methodology and reflected the most sensitivity to the mental health milieu was prepared by the Centre for Research and Education in Human Services. After discussing suggested refinements to the methodology, the Committee negotiated a contract with the Centre to undertake the evaluation of the Psychiatric Patient Advocate Office.

ROLE OF THE COMMITTEE

In consultation with the research team, the Committee agreed on the role that it would play throughout the evaluation. Through direct requests to interested groups and agencies and by placing advertisements in all local newspapers in areas where provincial psychiatric hospitals are located, the Committee solicited submissions from the community. From December 1986 to May 1987 the Committee received over 100 submissions from various groups and individuals offering their views and experiences with the Psychiatric Patient Advocate Office and the advocacy needs of psychiatric patients. These submissions were shared with the research team. Because of promises of confidentiality made to many respondents, we have not appended a list of individuals who presented submissions. Appendix 2 contains the names of groups and organizations which prepared submissions.

We recognized that the formal request for written submissions might discourage some members of the community from expressing their views. Part of the research team's proposed methodology included organizing meetings with community members in all areas where provincial psychiatric hospitals are located. We used these meetings as a further vehicle for hearing the experiences and opinions of those who had direct contact with advocacy and the advocacy needs of psychiatric patients, particularly former patients. Members of the Committee attended nine community meetings to ensure that those who wished to express their views to us had an opportunity to do so.

Throughout the evaluation, the Committee monitored the collection of data in the ten provincial psychiatric hospitals and participated in the process of interpreting those data. Initially it was intended that the Committee would meet with the research team at five significant points during the evaluation to discuss the proposed method of data collection, the results of a pre-test at two hospital sites, the analysis of the data collected, a draft report and a final report. Ultimately, it was necessary for the Committee to meet with the research team on seven occasions during the evaluation. This expansion of the project arose directly as a result of two factors:

1. On December 16, 1986, the Attorney General announced the O'Sullivan Review of Advocacy for Vulnerable Adults in Ontario, which included consideration of psychiatric patients; and

2. Relying on its collective experience in the mental health area generally and with the provincial psychiatric hospitals specifically, the Committee provided other sources of data and offered other perspectives for data analysis.

While the primary focus of this evaluation has been the effectiveness and impact of the Psychiatric Patient Advocate Office, the prospect of a larger advocacy vehicle in Ontario necessarily added a new dimension. While the data relate essentially to the experience of the Psychiatric Patient Advocate Office, the analysis and presentation needed to be in a form that could assist with the future development of advocacy models generally. The O'Sullivan Report, entitled You've Got a Friend: A Review of Advocacy in Ontario was released after the evaluation report from the Centre for Research and Education in Human Services had been completed. Hence, our research team was not able to consider the relationship between its recommendations and the model suggested by the O'Sullivan Report. (Our Committee offers its views on some of the common issues at pages xxi to xxvi of its Report.)

NATURE OF THE EVALUATION

The context for this evaluation has been characterized by a number of factors which explain why qualitative analysis of data obtained from a large number of field interviews was the appropriate methodology:

a) While the most basic measure of effectiveness is a comparison of a program's achievement with its original mandate, the Committee concluded that the original mandate was cast amorphously in broad and vague terms. The Psychiatric Patient Advocate Office developed its own working mandate which reflected the orientation of its staff, its structure as an internal advocacy program and its experimental nature within an institutional context;

b) Advocates were inserted into an existing institutional structure with an entrenched hierarchy and a social dynamic that had evolved over many years;

c) Amendments to the Mental Health Act and the entrenchment of the Canadian Charter of Rights and Freedoms provided legal standards and procedural protections with which to address issues of fundamental justice, liberty and security of the person in respect of psychiatric patients;

d) Advocates who have faced the challenges of their new role within a changing system came to the staff with varying backgrounds and training.

Clearly, the Psychiatric Patient Advocate Office achieved successes which highlighted particular strengths in its structure and approach. It was inevitable, however, that its insertion into the institutional context of the provincial psychiatric hospital system would generate controversy and even resistance.

It has been the function of this evaluation to assess successes and failures, strengths and weaknesses, and intended and unexpected impacts, in order to determine how the advocacy needs of psychiatric patients can best be met in the future.

EVALUATION REPORT OF THE CENTRE FOR RESEARCH AND EDUCATION IN HUMAN SERVICES

The Committee is confident that the report from the Centre represents a comprehensive and objective assessment of the efforts, structure and internal organization of the Psychiatric Patient Advocate Office.

The evaluation acknowledges the valuable contribution made by the advocates working in the provincial psychiatric hospitals. It notes both the positive and negative impacts and makes various recommendations to enhance the positive aspects of the program while minimizing negative perceptions.

The report recognizes the need to clarify the role of advocates within the institutional context and the need to develop better channels of communication with hospital and medical staff. In the area of non-instructed and systemic advocacy, the Psychiatric Patient Advocate Office has not yet lived up to its potential. Expanded resources, clear policy and direction, and better co-ordination are needed to enhance its ability to deal with systemic issues and non-instructed cases, particularly with psychogeriatric and developmentally handicapped patients.

The issue of structure has been a central controversy since the inception of the Psychiatric Patient Advocate Office. The evaluation confirms the need for independence from the Ministry of Health, both in symbolic and functional terms, in order to avoid any perception of conflict of interest and any confusion of role which might impair the activity of the office. You will note that the evaluation recommends accountability to an independent board controlled by nominees representing the users of the mental health care delivery system.

RECOMMENDATIONS OF THE EVALUATION REPORT

After describing the data and reciting its findings in respect of the key issues defined by the Committee, the Centre for Research and Education in Human Services made the following recommendations:

(a) Effectiveness: Process and Perceptions of Patient Instructed Advocacy (see pages 23 to 60 of the Evaluation Report)

1. The PPAO should develop strategies for reaching out to educate non-client patients about the PPAO. These strategies need to include concepts such as patient meetings and patient government.
2. Ongoing systematic education of staff about rights and the mandate of the Advocate Office needs to be developed. This education should be designed to create a more positive image of the Advocate Office and to provide a needed balance to the more

adversarial image of its advocacy work. Special consideration needs to be given to how this education can influence those psychiatrists who are negative about the program.

3. A problem-solving/educational approach to the advocacy process needs to be re-affirmed as the primary approach for PPAO advocates. This approach should be reinforced through: an orientation program, ongoing professional development programs, and annual performance reviews. It must also be recognized, however, that certain circumstances require other advocacy approaches.

4. The PPAO Head Office needs to expand its pilot work in developing training sessions to enhance advocates' effectiveness with the advocacy process. The training should be in such areas as negotiating, how to promote self-advocacy, ways to escalate a case, and other needed advocacy strategies.

(b) Effectiveness: Non-Instructed and Systemic Advocacy

(see pages 61 to 86 of the Evaluation Report)

5. The PPAO needs to more clearly articulate the role of systemic advocacy and non-instructed advocacy within its mandate.

6. A full-time co-ordinator for systemic and policy issues would be added to Head Office staff; the co-ordinator needs to have skills in the areas of research, policy analysis, and strategies for change, as well as knowledge of psychiatric institutions, the broad mental health network, and government structure and processes.

   The role of the co-ordinator would be to:

   - develop a protocol or process for escalating systemic cases, monitoring events, and following up systemic issues.
   - develop guidelines for the documenting and monitoring of systemic files for local and provincial issues.
   - assist in the development of guidelines for non-instructed advocacy.
   - organize papers, policies and other materials so that they can be made available quickly to advocates.
   - be aware of all local systemic issues for the purpose of linking advocates with others who have expertise on particular issues.

- provide research and analysis support for both local and provincial issues.
- assume leadership, with the Provincial Co-ordinator, in representing the PPAO's policies to external groups.

7. Comprehensive strategies and principles need to be developed which would increase the effectiveness of non-instructed advocacy; this requires that the PPAO:

   - further develop guidelines for the non-instructed advocacy process and methods of appropriate interventions related to non-instructed cases.
   - collaborate with other voluntary associations to develop guidelines and suggestions for advocates on how to monitor psychogeriatric and mental retardation wards.
   - develop strategies with advocates to more effectively link non-instructed cases with systemic advocacy.

(c) Impact: On Individuals, Staff, Hospitals, and Policies

(see pages 87 to 131 of the Evaluation Report)

8. The PPAO needs to actively encourage and facilitate access for those patients who are currently underserved, including patients who are illiterate, non-English speaking, elderly or developmentally handicapped. This is in order that a greater number of patients be afforded the sense of assurance, support and protection now enjoyed by PPAO clients.

9. More extensive and simplified resources and outreach should be developed to inform and educate patients, staff and the community about rights and advocacy in a comprehensive and systematic way.

10. The PPAO needs to develop a clear outline of ways that advocates can be promoted as a resource to staff in the area of patients' rights and that the PPAO's image as a resource be developed by:

    - publicizing their contributions and accomplishments in the area of hospital, community and provincial policies.
    - co-operating with supportive staff to gradually build a more positive image of the advocate.
    - reciprocating and demonstrating an interest in and respect for the resources that staff can provide to the PPAO.

11. The Ministry should develop strategies and mechanisms to encourage respect for the rights of patients and promote patient autonomy, self-advocacy, and participation in treatment decisions.

12. The Ministry should direct its hospital administrators to be responsible for assuring that there be serious consequences for staff who intimidate or discourage patients from using the Advocate Office.

13. In order to further integrate rights and treatment, to reduce the "revolving door syndrome", and to strengthen the concept of "least restrictive alternatives", the Ministry of Health should develop a plan for strengthening community living and community treatment options.

14. The PPAO should articulate its role as a facilitator to ensure patients' involvement in the planning/ treatment process.

15. The PPAO needs to develop concrete materials which clearly explain the advocacy process; this should be shared with staff to alleviate their concerns that advocates encourage people to refuse treatment or hospitalization and to ensure that advocates themselves have a process to follow which can be monitored by Head Office.

16. The PPAO should meet with union officials to jointly determine strategies for getting staff support for patients' rights and for improving the image of the PPAO among front line staff.

(d) Structure (see pages 133 to 158 of the Evaluation Report)

* 17. An independent PPAO board should be established, funded primarily by a grant from the Ministry of Health, and this structural arrangement should:

- entrench the mandate of the PPAO in a provincial statute.

- consist of a consumer controlled Board, with a majority of members representing patients or former patients. The PPAO Co-ordinator would be an ex-officio member of the Board. Board members would be appointed by Orders-in-Council after direct consultation with all relevant consumer groups. The main commitment of all members must be to the goals of the PPAO.

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* See comments infra at page xix.

- ensure that the Board sets policy and makes major budget decisions.
- make the PPAO staff accountable to the Board.
- ensure that the Co-ordinator and the Board have ongoing access to the Minister and the Deputy Minister of Health.
- provide for a PPAO Annual Report to be tabled in the Legislature.

18. If the PPAO is incorporated into a larger province-wide advocacy structure, the structural arrangement described in the previous recommendation should be maintained.

19. Any province-wide advocacy model for vulnerable adults that is implemented should ensure that successful elements of the PPAO, as outlined in the aforementioned criteria, are incorporated into the program. Specifically that:

    - the primary responsibility of the advocate be to his or her client.
    - the advocates have a specialized knowledge of the particular institution or system within which they are working.
    - the program have minimal bureaucracy with centralized support and a coherent program for instructed, non-instructed and systemic advocacy.
    - the agency have a visible degree of independence from the organization that funds it and from the institution where it is located.
    - the orientation of the program emphasize therapeutic, legal, and social cases.
    - the access to client files, staff, policies, and facilities be guaranteed through legislation and/or contractual arrangements.
    - the program ensure that patients know that the advocate is on their side.

(e) Internal Organization and Resources (see pages 159 to 174 of the Evaluation Report)

20. The program should maintain and enhance opportunities for the advocates to develop more personal and professional support through:

- the allocation of more funds for informal meetings between advocates on local issues, and for routine visits to each advocate and hospital by the Provincial Co-ordinator.

- specific opportunities for dealing with personal and professional support issues.

- maintenance of the case conference mechanism, redesigned by program staff so that it is a more satisfying experience.

21. The principle of maximum input from everyone involved and a consensus-building approach to decision-making should be affirmed and supported by mechanisms outlined in the evaluation report.

22. A full-time co-ordinator for systemic and policy issues should be added to Head Office staff as discussed in Chapter IV.

23. Clinical consultants should be on retainer to the program for advice on clinical issues.

24. A second, full time secretarial position needs to be added to Head Office.

25. Once the structure of the program is determined, new terms of employment that address the need for longer contracts and benefits for advocates and central staff should be developed for all PPAO personnel.

26. An expanded orientation program for new advocates needs to be designed and implemented.

27. In clarifying the new structure, the role of the Advisory Committee, if any, will need to be determined.

28. Program guidelines should be reviewed and updated including matters such as confidentiality and release of information.

29. Annual program objectives need to include the definition of strategies and responsibilities and the implementation of these objectives should be monitored by Head Office.

30. Guidelines for minimum standards of documentation and recording should be developed and enforced for both individual and systemic cases so that files can be followed by other program personnel and so that advocacy activities are more defensible.

31. The PPAO should continue to review its data reporting system by conducting a formal needs assessment and then updating its documentation and computer system accordingly.

32. The program needs to begin to develop an ethics casebook and standards of ethical conduct.

33. Head Office should acquire a word processor for the efficient production and revision of documents.

34. Additional travel resources need to be allocated to the program to accommodate: more frequent sub-group meetings; more visits to the hospitals by the Co-ordinator and the new systemic co-ordinator; orientation and continuing education opportunities.

35. The PPAO should receive funding to assist in implementing the administrative recommendations of this evaluation.

(f) Future Directions and Expansion (see pages 175 to 189 of the Evaluation Report)

36. The PPAO should be the focal point for planning and co-ordinating any expansion of advocacy services for psychiatric patients to ensure that key elements of the PPAO be safeguarded.

37. The mandate of the PPAO should be expanded to include outpatients, former patients with concerns related to the institution and persons seeking the services of the institution.

* 38. The PPAO should be expanded to include the four other psychiatric hospitals in Ontario and a variety of administrative and implementation issues should be carefully studied prior to the expansion.

39. Any additional PPAO expansion should be "phased in" in a manner which is coherent with the development of any province-wide advocacy structure, and these expansions should include:

    . development of pilot projects which would adapt and modify the PPAO model to other Ministry of Health facilities which service psychiatric patients, including Homes for Special Care and Approved Boarding Homes.

    . a comprehensive study to consider how to adapt and modify the key elements of the PPAO model to a community advocacy program.

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* See comments infra at pages xix to xx.

COMMENTS ON THE RECOMMENDATIONS

Subject to the remarks below in respect of Recommendation 17 and Recommendation 38, the Committee is satisfied that the recommendations of the Centre for Research and Education in Human Services are supported by the data. We adopt them as essential steps in the future development of the mental health care delivery system in Ontario.

One aspect of Recommendation 17 deals with the future funding of the Psychiatric Patient Advocate Office. The argument supporting this recommendation is that, given the important role which the support of senior Ministry of Health officials has played in the efforts of the Psychiatric Patient Advocate Office, as noted at pages 143-146 of the Evaluation Report, continued funding creates at least an enhanced opportunity for continued co-operation. One Committee member dissented from the recommendation that funding from the Ministry of Health be continued. The dissent flows from a concern that funding from the Ministry of Health presents a potential source of inappropriate influence.

If in the future the Psychiatric Patient Advocate Office is integrated into a larger province-wide advocacy network, funding will be a significant issue. The Committee recommends that consideration should be given to a multi-ministerial funding pool. This would preserve the enhanced opportunity for co-operation as argued by our research team and would also blunt any concern about the potential for control or manipulation.

With respect to Recommendation 38 dealing with expansion to the other psychiatric hospitals in Ontario, one Committee member expressed the concerns that: the evaluation contains only limited data relating to these hospitals; the four hospitals are not identical; the patient populations in the four hospitals cannot be characterized as entirely similar to the populations in the provincial psychiatric hospitals; and the four hospitals are governed by community boards. However, given the advocacy needs of psychiatric patients in general, and the importance of an external advocacy vehicle as noted in the evaluation, the majority of the Committee accepts the recommendation that the Psychiatric Patient Advocate Office should be expanded to serve the needs of patients at the Clarke Institute, the Royal Ottawa Hospital, the Sudbury Algoma Hospital and Homewood Sanitarium. The Committee recognizes that any advocacy vehicle for the Clarke Institute should explicitly include the patients at METFORS.

Aside from the general recommendations offered in the Centre's evaluation, much information was related to operational issues of a practical and situational nature which were too detailed, and sometimes too personal, to be included in the report. Funds should be made available to enable the Psychiatric Patient Advocate Office to consult with the research team in order to take advantage of these data and improve its day-to-day functioning.

IMPLEMENTATION OF THE RECOMMENDATIONS

Our Committee urges that the process of implementing the recommendations from this evaluation commence as soon as possible. Many of the recommendations will require an expansion of the Psychiatric Patient Advocate Office with respect to both its internal organization and its mandate. This expansion will require further resources. The Committee recognizes the underfunding which pervades the mental health care delivery system in general. We recommend that the resources needed to fund the expansion of the Psychiatric Patient Advocate Office be provided from new funds rather than through a rechannelling of funds currently allocated for other purposes, particularly treatment needs. The evaluation notes the conflicts which have arisen between advocates and treatment staff. Any rechannelling of funds from treatment areas will only exacerbate existing tensions.

We recognize that some recommendations can be implemented immediately while others will generate various options for implementation and will require further consideration at the policy level. The O'Sullivan Report has recommended a "shared" advocacy model (see _You've Got a Friend: A Review of Advocacy in Ontario_, Ministry of the Attorney General, 1987, at pages 120-155). The model anticipates the development of advocacy vehicles through the local initiative and management function of seven regional boards. It recommends the integration of the Psychiatric Patient Advocate Office into this network with the retention of internal accountability by placing the Provincial Co-ordinator within the central office component.

While our research team did not have the opportunity to consider the impact of the model ultimately recommended in the O'Sullivan Report, our committee recognizes that the issue of future integration into a larger province-wide network will require careful thought and planning. In particular, the following questions need to be addressed:

(a) Future Integration

The O'Sullivan Review reflects the seriousness of attention being paid to the advocacy needs of vulnerable adults in various contexts. The integration of the Psychiatric Patient Advocate Office into any future province-wide model is a complex, multidimensional issue. A number of aspects of this evaluation bear directly on that question.

First, it is important to note that while advocacy adopts many of the skills and strategies traditionally employed by lawyers, social workers and health care professionals in assisting those in need of care and help, the role of the advocate represents a unique amalgam of these skills and strategies. As part of the development of advocacy as an essential element in contemporary human service delivery systems, the Psychiatric Patient Advocate Office cannot--and should not--remain aloof from a provincial advocacy network. Its experience within the provincial psychiatric hospitals will provide substantial assistance both in the development of models for other contexts and in the training of advocates. More important, the resources needed to train advocates and support advocacy initiatives should be rationalized and shared. The evaluation has highlighted the need for special attention to therapeutic and social issues and the consequent need for specialized training on the part of the advocates who work in institutional contexts. Accordingly, while integration into a province-wide network may be an important step in advancing advocacy for psychiatric patients, a discrete coherent program to address the special needs of psychiatric patients, including non-instructed and systemic cases, must be preserved.

We recognize that the maintenance of specialized services for particular sub-groups of vulnerable adults may tend to entrench the process of stigmatization and labelling which impairs the full ability of people to integrate freely and without discrimination in our community. Some social goals, however, can only be achieved incrementally. This is illustrated by the history of the Psychiatric Patient Advocate Office. The initiative of the Ministry of Health in establishing this office was a significant step in the development of advocacy for psychiatric patients. However, it is now time for the office to move into a more mature and autonomous role. Similarly, the expansion of advocacy into other contexts and environments where vulnerable adults live must proceed stage by stage with special attention to the needs of each context and environment. Within a large advocacy network, there are general skills and broad resources which can be shared amongst advocacy vehicles. It is our view that, at least in the early years, specialization will be essential to ensure that each advocacy vehicle grows from strong roots. Models must be designed and advocates trained especially for the communities and institutions in which they will operate.

(b) Constitution of the Governing Board

As documented in the Evaluation Report from the Centre for Research and Education in Human Services, the Psychiatric

Patient Advocate Office should be accountable to a specialized governing board. The board established to direct and oversee the Office should be user controlled. This is essential especially in light of the need to address more vigorously and effectively non-instructed cases and systemic issues.

The manner of constituting this board is not without controversy. Clearly, it should be representative of the community of patients and former patients. As well, all Committee members recognize the value which would flow from responsible input from the professional and service-provider communities. One Committee member suggested that a representative of the Ontario Public Service Employees Union should sit on the governing board. Some Committee members noted the subtle influences which professionals sometimes inject into the decision-making dynamic and, more important, the recognized need for both functional and symbolic independence as shown by the Evaluation Report.

Our consideration of the recommendations for an independent structure produced two options:

1. A decision-making board with a majority of members who are patients and former patients and a minority representing the community at large, including professionals and representatives of the service-provider community; or

2. A decision-making board with a majority who are patients and former patients and a minority of members representing the community at large, but excluding mental health care professionals and representatives of the service-provider community. Representatives of the latter group would serve as members of a permanent advisory body.

Regardless of which option is chosen, a specialized independent governing board is fundamental to the evolution of the Psychiatric Patient Advocate Office.

(c) Community Advocacy

Vulnerable adults in Ontario include many who live in institutional settings and many who live in the community. The evaluation report from the Centre for Research and Education in Human Services has recommended the expansion of the mandate of the Psychiatric Patient Advocate Office to include outpatients. Of course, there are many people whose "vulnerability" is a function of mental health and who live in the community but cannot be characterized as outpatients. This group has special needs, many of which are similar to those of outpatients in respect of both therapeutic issues and the persistent problems of discrimination in housing, employment, and education. A province-wide advocacy network will need to develop a vehicle for community advocacy which is capable of addressing the needs of vulnerable adults in each geographical community. Of particular importance will be sensitivity to local problems and knowledge of local services and resources.

A major issue for integration with a province-wide network is the question of how advocacy can be provided in a coherent manner to those who, at various times, may be inpatients, outpatients, or persons not receiving services from a hospital. As well, with changes in situation, the problems which confront people may change, but their history and personal qualities remain the same. An advocacy model must be designed to accommodate changing situations. Two options are available:

1. The psychiatric patient advocate can follow the client into the community. This continuity with an individual advocate will enhance the advocacy relationship, avoid bureaucratic problems of file allocation and ensure that people do not slip accidentally into a crack in the system; or

2. Psychiatric patient advocacy can be restricted to inpatients and outpatients. As a person moves into the community, advocacy needs can be addressed by community

advocates sensitive to local problems and knowledgeable about local resources.

It is clear that both of these options present advantages and disadvantages. While continuity is a valuable goal, advocacy both within an institution and within the community will require diverse skills and training. As well, work in the community will necessarily remove the advocate from the institutional context in which his or her presence is a valuable ingredient. The evaluation has noted the importance of specialized training for psychiatric patient advocates particularly with respect to therapeutic and social issues.

The adoption of a "location based" advocacy network, rather than a "client based" advocacy network, presents other practical demands in order to ensure that discontinuity does not impair the advocacy function. Communication between institutional and community advocates would necessarily need to be maintained carefully and consistently. Assuming that functions could be co-ordinated effectively, this option would permit that maximum energy and attention be paid to the respective contexts. This specialized approach may be an important choice given the primary impact of institutional structure, community resources and community attitudes on the advocacy needs of vulnerable adults who live within them.

RIGHTS AND TREATMENT

A cautionary note must be offered about the perception of conflict between rights and treatment. It is legitimate to ask about the extent to, and the manner in, which the exercise of legal rights interacts with the delivery of prescribed treatment. It is wrong, however, to dichotomize the discussion in the form of "rights versus treatment", as was apparent from the data collected in this evaluation. The two objectives are not, and cannot be viewed as, mutually exclusive or antagonistic.

Autonomy and respect for the integrity and dignity of the individual are fundamental values which strengthen the fabric of our community. The inviolability of the human person is guaranteed and protected by our Constitution.

Participation in the planning and delivery of therapy is a manifestation of these values. It is also a significant aspect of progress towards re-integration and responsible interaction with the community. Advocacy, in both its informing and representative functions, is a necessary element in a contemporary therapeutic process which responds medically, ethically and humanely to those in need of care and treatment.

CONCLUSION

During a time when a number of factors have generated change into the mental health care delivery system in Ontario, it should be expected that some participants will react to change either by questioning its efficacy or resisting its implementation. We are observing a period in Ontario during which both legal responses and medical responses to the condition of psychiatric patients are evolving. The Psychiatric Patient Advocate Office has played a positive and necessary role in this evolution. The evaluation has both confirmed the valuable contribution of the Psychiatric Patient Advocate Office and exposed some of its limitations and inadequacies. Like the mental health care delivery system, the Psychiatric Patient Advocate Office needs to evolve.

The Committee recognizes the importance of advocacy as an element in the therapeutic process and, except as noted, we support the recommendations contained in the evaluation report of the Centre for Research and Education in Human Services. With the implementation of these recommendations, we will see the maturation of the Psychiatric Patient Advocate Office. Its clients, their families and the community will benefit as it grows from the uncertainty of an experimental program into the stability of an entrenched advocacy agency.

APPENDIX 1

EVALUATION COMMITTEE MEMBERS

Chairman

Professor Allan Manson
Faculty of Law
Queen's University
Kingston

Members	Nominating Agency
Ms. Sue Campbell Parkdale Community Legal Services Toronto	Coalition on Psychiatric Services
Ms. Pat Capponi Parkdale Activity and Recreation Centre Toronto	Advisory Committee to the PPAO
Mr. James Clancy President Ontario Public Service Employees Union Toronto	Ontario Public Service Employees Union
Mr. Brian Davidson Director, Social Policy Canadian Mental Health Association - Ontario Division Toronto	Canadian Mental Health Association - Ontario Division
Mr. Derek Day Board Member Canadian Mental Health Association, Sudbury Branch	Canadian Mental Health Association, Sudbury Branch
Ms. Ruth Gallop Research Fellow Department of Psychiatry Toronto General Hospital	Advisory Committee to the PPAO
Professor Brian Mazer Faculty of Law University of Windsor	Community Advisory Boards for the Provincial Psychiatric Hospitals
Ms. Carla McKague Senior Litigation Counsel Advocacy Resource Centre for the Handicapped Toronto	Advocacy Resource Centre for the Handicapped

Dr. D. Wasylenki Director Continuing Care Division Clarke Institute of Psychiatry Toronto	Ontario Psychiatric Association

Ex Officio Members

Ms. Debi Mauro	Director, Community Mental Health Branch (formerly Director, Mental Health Operations Branch), Ministry of Health
Dr. Tyrone Turner	Past Co-ordinator, PPAO
Ms. Mary Beth Valentine	Co-ordinator, PPAO

WRITTEN SUBMISSIONS*

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Canadian Association of Psychoanalytic Psychotherapists for Children

Canadian Mental Health Association, Kent County Branch

Canadian Mental Health Association, Kingston Branch

Canadian Mental Health Association, Metropolitan Toronto Branch

Canadian Mental Health Association, North Bay Branch

Canadian Mental Health Association, Sarnia-Lambton Branch

Canadian Mental Health Association, Sudbury Branch

Canadian Schizophrenia Foundation, Thunder Bay Branch, Nutrition and Behaviour Group

Community Occupational Therapy Associates

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Criminal Lawyers' Association

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Hamilton Psychiatric Hospital, Community Advisory Board

Hamilton-Wentworth District Health Council

Hastings and Prince Edward Counties Health Unit

Dr. P.C.S. Hoaken, Professor of Psychiatry, Queen's University, Kingston

---

* Because of promises of confidentiality made to many respondents, we have not included the names of patients, staff or family members who made submissions.

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Office of the Public Trustee

The Ombudsman/Ontario

Ontario Association of Professional Social Workers

Ontario Friends of Schizophrenics

Ontario Friends of Schizophrenics, Hamilton Chapter

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Ontario Friends of Schizophrenics, Peterborough Chapter

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Registered Nurses' Association of Ontario

Rideau Valley District Health Council

The Honourable John P. Sweeney, Minister of Community and Social Services

Timiskaming Health Unit

Whitby Psychiatric Hospital, Community Advisory Board

ADVOCACY IN PSYCHIATRIC HOSPITALS

EVALUATION OF THE PSYCHIATRIC PATIENT ADVOCATE OFFICE

This study was completed for the Psychiatric Patient Advocate Office Evaluation Committee, which was appointed by the Minister of Health to oversee the evaluation.

The evaluation was conducted by:

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FOREWORD

The rapid expansion of the concept and practice of advocacy in the last decade reflects our society's increasing concern that human rights be protected and enhanced. The Psychiatric Patient Advocate Office was introduced in Ontario in 1982 as a mechanism to respond to the needs and concerns of psychiatric patients in Ontario's provincial psychiatric hospitals.

This study has been a comprehensive evaluation of the effectiveness, impact, structure, internal organization, resources, and expansion possibilities of the Psychiatric Patient Advocate Office.

Recently there has been intense interest in professional advocacy for vulnerable adults. By identifying a number of themes, issues and findings, we believe this study will have enormous implications for the development of advocacy models in other jurisdictions . The qualitative nature of the data we present will also allow readers to gain an indepth understanding of the complexity of advocacy in institutional settings.

We wish to acknowledge the support of a number of individuals and groups. The Evaluation Committee that worked with us for eight months was extremely helpful. Their deliberations on complex issues as well as their thorough reviews of material generated by the research team continually focused the evaluation process. A special thanks is extended to chair Allan Manson, who went 'beyond the call of duty' in his support, constructive criticism, and encouragement of the research team.

The Psychiatric Patient Advocate Office has been immensely helpful during this entire study. They willingly 'opened their files' and responded quickly to all of our requests. We especially appreciated the support from the new Provincial Co-ordinator, Mary Beth Valentine, who had to get involved in this evaluation as one of her first tasks; and from Susan Atkinson, Executive Assistant, who continually organized information which we needed.

We received excellent support from all ten hospitals. Advocates and rights advisors did a tremendous amount of preparation prior to our hospital visits and provided any information we needed while on site. Thanks are also extended to hospital administrators and their staff for arranging interviews and providing the data we needed, and conducting a hospital tour for us. The hospitality extended by all of these groups made our hospital visits very comfortable.

Finally, to all respondents who answered our questions, we say 'thank you.' Patients, family members, hospital staff, Ministry Officials, and community members who attended community meetings or who sent the Evaluation Committee a submission - each of your perceptions has been analyzed carefully, and in concert with other views, has enabled us to construct a 'wholistic' picture of advocacy in psychiatric institutions. The research team, including our advisors, did very thorough work at each stage of the evaluation.

We believe this qualitative study will be directly usable not only in mental health, but in other fields which are concerned about institutional advocacy.

John Lord August, 1987
Project Director

Chapter I

INTRODUCTION

This report presents the findings from an evaluation of the Psychiatric Patient Advocate Office (PPAO), a program established by the Ontario Ministry of Health in 1982 to advocate on behalf of patients in Ontario's ten Provincial Psychiatric Hospitals.

FACTORS ENHANCING THE DEVELOPMENT OF ADVOCACY

The development of advocacy models and practice is a recent phenomenon in the history of human services. While advocacy has probably always taken place on behalf of vulnerable, disadvantaged persons, it has only been in the last two decades that advocacy has been conceptualized as a key element in areas such as mental health, mental retardation, and aging. As Wolfensberger (1977) noted, the term "advocacy" was rarely found in human service literature prior to 1970. By the 1980s, however, the literature in a wide variety of fields began to mention the concept of advocacy and to review a variety of advocacy programs and models (Bloom and Asher, 1982).

Society's interest in advocacy for people who have experienced the mental health system can be attributed to a number of factors including:

- *the impact of general consciousness about* **human rights.** The Canadian Charter of Rights and Freedoms, enacted in 1982, reflects our society's concern for the rights of minorities. Litigation and legal advocacy has a much longer history in the United States, where reform in mental health has been tied more directly to the American constitution and legal precedent. As a result, professional advocacy programs are much more developed in the United States than in Canada (Bloom and Asher, 1982).

- *the effect of new* **ideologies** *in mental health, including normalization, community based services and integration* (Bradley & Murphy, 1980; Wolfensberger, 1973). These values and practices have raised expectations about what disadvantaged persons are capable of achieving.

- *the impact of the consumer* ***self-help movement.*** The voices of articulate individuals and self-help groups who have had direct experience with the mental health system are beginning to be heard. They speak out about injustices, powerlessness, and community-based alternatives (Chamberlin, 1978; *Phoenix Rising*, 1985).

- *The increasing* ***demedicalization*** *of disabilities in the last decade* (De Jong, 1979). The *Obstacles Report* (Special Committee on the Disabled and the Handicapped,1981), for example, represents a significant shift in thinking about the social, economic, and political aspects of disability. In mental health, the 'rights versus treatment' debate often reflects this process and struggle.

- *The growing body of literature on the* ***limitations of the asylum*** *or institution as an appropriate place for treatment and support* (Blatt, 1970; Bloom and Asher, 1982; Goffman, 1961). As a result, some have argued, that given the nature of institutions, advocates are a primary and necessary safeguard against abuse.

Within this atmosphere of growing attention to human rights and advocacy for more vulnerable people, mental health systems in the early 1980's began to consider the implications for people labelled psychiatrically disabled. The history of psychiatric hospitals, however, had shown minimal emphasis on civil and human rights. The First Report of the Psychiatric Patient Advocate Office (1984) highlights possible reasons that existing civil and human rights had penetrated psychiatric facilities with limited depth:

> This lack of penetration may have been caused by a number of factors, namely: the patient's disability; the regressive effects of hospitalization on individuals; the marked power imbalance between the patient and the treating professional; and the health care system's traditional focus on health care, rather than on rights protection (p.ii).

DEFINING ADVOCACY

Despite the rapid development of advocacy concepts and programs, there appears to be little consensus to date on either the definition or the purpose of advocacy. A decade ago, Taylor (1977) documented the confusion which results when different groups have varying expectations of the goals and function of advocacy. More recently, Milner (1986) has argued that a myth of advocacy has developed resulting in various people and professional groups claiming to perform the role of advocate.

Most simply, advocacy has traditionally meant "to plead the cause of another". Advocacy has also come to mean, "speaking for oneself". Wolfensberger (1977) has noted that advocacy must also involve a depth of feeling and commitment in advancing a cause and calls for "more than what is done routinely." Finally, several authors have noted that effective advocacy must be structured so that advocates are free from conflict of interest in order to fully represent their clients (Wilson et al., 1977; Wolfensberger, 1977). It also appears that advocacy means "representing a client's wishes, whenever such wishes are ascertainable, and upholding the civil, legal, and human rights of individuals and groups of individuals" (Van Ness & Perlin, 1977).

Effective advocacy must be approached on many different levels (Bloom and Asher, 1982; Savage, 1980; Wolfensberger & Zaula, 1973, 1977). This is because the issues for advocacy are complex and the dynamics of social change are varied. As well, there are discrepancies between legal rights and what we believe to be basic human rights. "Legal rights" commonly refers to specific entitlements entrenched in and enforceable by law and legislation. Human rights is a more expansive concept which aspires to protect universal human values based on idealistic premises. For example, see documents such as the United Nations Declaration of Human Rights and the International Covenant on Civil and Political Rights. It is the gap between legal rights and human rights that has persuaded many people that the struggle for improvement, to be effective, needs to be fought *on both human and legal* fronts.

Obtaining and securing rights involves many approaches, different skills, and a variety of strategies. Four different types of advocacy have been documented in the literature: self-advocacy, individual or case advocacy, agency advocacy, and collective advocacy. The first two types, while often useful for solving individual dilemmas, rarely produce systemic change because they focus only on the individual's needs. Agency advocacy is hampered by conflict of interest more than other types because the advocates are frequently professionals who work for the agency. Finally, collective advocacy is the approach which is most free from conflict of interest and, because of its collective nature, tends to have more impact on systemic and policy change. This is the type of advocacy done by voluntary advocate associations and self help groups. Despite the limitations of each type of advocacy, an amalgamation of approaches may be needed to bring about social changes and improved rights (Biklen, 1974; Lord, 1981).

THE PSYCHIATRIC PATIENT ADVOCATE OFFICE

In Ontario, the debate about the rights of psychiatric patients was influenced in the early 1980s by three issues:

- The proclamation of Section 66 and Section 67 of the Mental Health Act, which provided procedures whereby involuntary patients have to be given notice in writing of their right to seek review of their certification and provided more procedural safeguards in hearings.
- The development of a coalition of interested groups which lobbied for an external advocacy program following inquests into the deaths of three psychiatric patients.
- The entrenchment in April of 1982 of the Canadian Charter of Rights and Freedoms.

In May 1982, the Minister of Health announced his intention to establish a Psychiatric Patient Advocacy Program for the Provincial Psychiatric Hospitals. From its inception, the mandate of the Psychiatric Patient Advocate Office (PPAO) has had a dual focus. The primary emphasis has been on providing assistance to individual patients in regard to their inquiries, concerns, and complaints. This individual case advocacy approach continues to be the predominant focus of the program. The second component involves what the Minister in 1982 called "making recommendations to hospital administrators and the Ministry's Mental Health Division." This aspect of systemic advocacy has been an important thrust of the program and is initiated either by advocates at the hospital level or by the Psychiatric Patient Advocate Office at the provincial level.

BASIS OF THIS EVALUATION

As the first major professional advocacy program in the health field in Canada, the Psychiatric Patient Advocate Office has received much attention. As with any new program, a range of issues which need to be addressed by the program have emerged. In many ways, this is a unique time to be studying advocacy. Many groups, such as the Advocacy Resource Centre for the Handicapped and Concerned Friends of Ontario Citizens in Care Facilities, have noted in submissions that they believe that more extensive, professional and voluntary advocacy is needed in order to address the needs of vulnerable people. This evaluation of the Psychiatric Patient Advocate Office represents an important source of information which not only relates to the future of the PPAO, but which also should provide helpful insight for people who are considering formalized advocacy systems and programs in other contexts.

The current evaluation appeared particularly appropriate and timely for the following reasons:

- The Minister of Health's initial promise of an evaluation of this program within eighteen months of its inception.
- General concerns about professional advocacy and whether it can function within a complex, hierarchical human service structure.
- The recognition of different types of advocacy and how they may be practised within an advocacy structure.

Several important research and conceptual frameworks were helpful in organizing these issues for study and evaluation (Bloom and Asher, 1982; Bradley and Murphy, 1980; Milner, 1986). A review of previous studies pointed to the need for a comprehensive evaluation which would examine both the process and outcomes of the Advocacy program.

Mandate of the Evaluation

The Evaluation Committee for the Psychiatric Patient Advocate Office was appointed by the Minister of Health in 1986. It is composed of representatives from various consumer, professional, labour, and advisory groups which play the major roles in the delivery of mental health care in Ontario. The Committee's mandate was to design the terms of reference for this evaluation and to oversee its completion.

The seven major areas to be evaluated were:

1. *effectiveness*, including a description of the basic case work process used by advocates, patient satisfaction, types of cases dealt with by advocates, and perceptions of others about the advocacy process.
2. *effectiveness*, particularly related to non-instructed advocacy and systemic advocacy.
3. *impact* of the program on individuals, staff, rights and treatment, hospitals policies and procedures, and other systems.
4. *structure*, especially the issue of the independence of the program.

5. *internal organization*, including issues of communication and support.

6. *resources*, including personnel, equipment and financial support.

7. *future directions*, including possible expansion of the program and the potential for transferring the program to other settings.

DESCRIPTION OF THE PROGRAM

When the Psychiatric Patient Advocate Office (PPAO) was established in the Spring of 1982, the program was the first province-wide program of advocacy in institutions in Canada. The unique component of the program announced by the Minister of Health was the appointment of a person to act as an advocate on behalf of patients in each of the ten provincial psychiatric hospitals. The Minister, in a press release, said that initially the main duties of patient advocates would be to:

- investigate concerns, inquiries, and complaints.
- assist in referring patients to appropriate services, including legal services, and outside resources; and
- make recommendations to hospital administrators and to the Ministry's Mental Health Division on how to improve the overall system.

In November, 1982, the Minister of Health appointed Dr. Tyrone Turner as the Provincial Co-ordinator of the Psychiatric Patient Advocacy Program. Because the field itself was so new, the Minister specified only the bare essentials of a structure for the program - leaving the development of its details to the Co-ordinator and an independent Advisory Committee. The Advisory Committee was comprised of people who had professional and personal interests in consumer rights, civil rights, and psychiatric treatment issues. The Advisory Committee's purpose was to advise the Co-ordinator of the program on program content and delivery, to assist in promoting advocacy for psychiatric patients, and to assist in providing the program with an image of independence. The Committee was also expected to assist the Co-ordinator with the preparation of the program's annual report for submission to the Minister.

After some time of development and adjustment, the goals of the program were established:

1. to advance the legal and civil rights of psychiatric patients in all provincial psychiatric hospitals by means of both individual case work and systemic advocacy.

2. to inform the patient, family, hospital staff, and the community about patients' legal and civil rights.

3. to assist, facilitate [self-advocacy] and help resolve the complaints made by psychiatric patients by providing an avenue for resolution through negotiation according to the patient's instructions.

4. to investigate alleged incidents and to assess institutional and systemic responses to these incidents.

5. to refer patients, when necessary, to outside community advocacy resources such as community organizations, lawyers, or physicians who may offer a second opinion (First Report of PPAO, 1984).

Eight of the provincial psychiatric hospitals have one patient advocate: Brockville, Hamilton, Kingston, Lakehead in Thunder Bay, London, North Bay, St. Thomas, and Whitby. Queen Street Mental Health Centre in Toronto and Penetanguishene Mental Health Centre (which includes a Regional Centre and Oak Ridge, a maximum security mental health centre) each have two advocates.

Each advocate reports to the Co-ordinator of the PPAO. The Co-ordinator, who works out of a central office in Toronto and is responsible for the overall program, officially reports directly to the Deputy Minister of Health. On a more informal level, most of the day-to-day reporting is to the Assistant Deputy Minister in charge of Mental Health.

While the Psychiatric Patient Advocate Office is an internal advocacy program in the sense that it is situated within the Ministry of Health, it was often defined in the early years as being "quasi external", because advocates did not report to anyone in the hospitals, and the provincial Co-ordinator had a high degree of independence in his reporting relationship with the Deputy Minister. Advocates, however, were encouraged to provide information to hospital administrators and to develop regular contact with the hospitals' Community Advisory Boards.

The program is described as primarily reactive, in that advocates are expected to "take instruction" from patients. Most of the early activity of the advocates reflected the specific concerns of hospital in-patients who came forward with complaints. As described in an article published by staff of the program (Atkinson et al., 1985), patients' rights and needs, as expressed to the advocate, can be grouped into three main categories:

- **Quality of life** (social rights advocacy) - issues which include privileges, economic status, access to religious services, contact with family and friends, etc.
- **Quality of care** (therapeutic advocacy) - issues such as therapeutic alternatives, second opinions, choice of care-giver, discharge plans, etc.
- **Self-determination** (legal advocacy) - issues such as informed consent, access to clinical records, review of committal, compulsory treatment, etc.

As well as the Co-ordinator and the twelve advocates, the PPAO has two main resource people in the central office. One is an administrative assistant and information gatherer for the program; the other serves as legal advisor. In addition, in March 1986, the Ministry of Health and the Ontario Legal Aid Plan placed rights advisors in each of the ten hospitals. In compliance with the Mental Health Act, they provide rights information to individuals who have been involuntarily committed to the hospital. The rights advisors are attached to the advocate's office and spend half of their time assisting the advocate with office work such as correspondence with families and agencies, follow-up, and documentation of cases.

At the inception of the PPAO program, the advocates were provided with complete access to wards, patients, and documents through designation pursuant to Section 5 of the Mental Health Act. Although the program was not given any enforcement or interventionist powers, it was intended that the advocates would have substantial access to information and people in the hospitals.

While advocates primarily respond to instructions from patients, there are a number of patients in each hospital who are unable to give instructions. These non-instructed cases, while forming a small percentage of the work, are an important part of the advocate's mandate. Because the advocate is concerned with *all* patients and with systemic advocacy, there is a clear role for proactive advocacy work.

SETTING THE PROGRAM IN CONTEXT

The mandate and program of the Psychiatric Patient Advocate Office must be understood in the context of provincial psychiatric hospitals and in substantive mental health issues in the 1980s.

The mental health system in Ontario has a very strong hospital component. Although several of the hospitals reduced their population in the 1970s, the last few years have seen the population of psychiatric hospitals level off somewhat. The Ministry of Health funds various mental health facilities within the institutional sector including ten provincial psychiatric hospitals, four specialized psychiatric hospitals, and over sixty general hospital psychiatric units. The responsibility for funding children's mental health services rests primarily with the Ministry of Community and Social Services.

Provincial Psychiatric Hospitals

The ten provincial psychiatric hospitals are found throughout the province. Half of all hospitals are on the outskirts of towns, reflecting the values of an earlier era that believed in isolating mentally ill people from the larger community. The remaining hospitals are part of urban communities, more often as a result of encroachment rather than design. We also noted a difference between northern and southern facilities, primarily in the relative lack of northern community resources and professional staff, and in the much larger catchment areas northern hospitals are expected to serve (see Appendix A).

The Mental Health Centre in Penetanguishene is actually a special case. It consists of two centres, the Regional Mental Health Centre and Oak Ridge. The Regional Mental Health Centre is similar to the other nine provincial psychiatric hospitals; it is worth mentioning, however, that there is a significant shortage of trained psychiatrists at this Centre.

Oak Ridge, originally known as the Criminally Insane Building, was built in 1933 for 150 patients. Oak Ridge, as the building became known, had to be expanded in 1957 to accommodate 300 patients in total. With the introduction of new treatments, the possibility of transferring patients to less secure hospitals became a reality. In 1957 the Lieutenant Governor's Advisory Board of Review was established to oversee the process of transfers (Hucker, 1984).

Oak Ridge is the sole maximum security psychiatric facility for men in the province of Ontario. Its patients include:

- those charged with criminal offences who are sent for assessment by the courts.

- those found unfit to stand trial because of mental disorder.
- those acquitted of a crime by reason of insanity.
- those found to be seriously mentally ill during incarceration.
- those who have never been formally charged with a criminal offence, but who are considered unmanageable or too violent in ordinary psychiatric facilities (this comprises almost half the population).

Because of growing concerns about the appropriateness of Oakridge's programs, mixed patient population(different legal status), and patients' rights, a committee was struck by the Ministry of Health in 1984 to review Oak Ridge. The Hucker Report(1984) noted in their foreword that:

> It [Oak Ridge] ...was originally constructed along prison lines. Although some changes, structural, administrative and attitudinal, have occurred, especially in the past few years and its central role in the province's mental health and criminal justice systems is undiminished, nevertheless it has experienced serious difficulties including the recruitment of professional staff, attendant staff-management relations, and quality of care. More recently there have been allegations from patients that the hospital violates their rights under the *Charter of Rights and Freedoms* (p. ii).

All ten provincial psychiatric hospitals appear to be similar in design and structure. Each hospital has an administrator, a psychiatrist-in-chief, and the usual professional staff including psychiatrists and physicians, social workers and nurses. Each hospital also has a variety of support professionals including occupational therapy, recreation, and sometimes vocational services. The more rural ones also tend to have "outreach" departments which provide services to patients who are returning to their home communities.

The role that each hospital plays is determined in large part by the network of psychiatric services within which it is located. To take extreme examples, Queen Street Mental Health Center, in downtown Toronto, will play a much more specialized role than Lakehead Psychiatric Hospital in Thunder Bay, where alternative services are much less available. Because of this, what is true of one hospital cannot necessarily be generalized to the other nine. All hospitals are run by the Ontario Government, and each hospital is expected to develop its own policies and procedures within the context of the Mental Health Act.

The hospitals and their catchment areas range in population from 237,000 (Lakehead) to almost 2 million (Queen Street); and from largely rural to largely urban. Those with large areas generally have smaller populations, and vice versa. While most hospitals are affiliated with a medical school, only four share a city with one, while others are in rural settings, and may be among the major industries in the town where they are located (see Appendix A).

The hospitals range in size from a population of about 225 up to about 700 patients. Field notes from our research team indicate that, for many patients, the hospital becomes a "total institution" (Goffman, 1961). Despite recent improvements in Ontario's psychiatric hospitals, such as affiliations with universities and increases in medical staff, Talbott (1978) claims that the total institution still exists when a system tries to accommodate most aspects of a person's life under one roof for an extended period.

It is often difficult for people's needs to be met adequately in this environment because of "model incoherency" (Wolfensberger and Thomas, 1983). When several models (medical, custodial, social, recreation, vocational) are expected to function at the same location, one or two models usually dominate, resulting in unmet needs in the other areas. In psychiatric hospitals, it is usually the medical and custodial models which dominate. Critics of psychiatric hospitals have further argued that they often tend to be more custodial than therapeutic.

A study by the Coalition of Psychiatric Services (1982) in Toronto highlighted several flaws in the mental health system including:

- the imposition of a system of order within hospitals that attempts to control behavior with such goals as bathroom or sunroom privileges.
- the regular transfer of patients from one part of the province to another - without notification or explanation to either patients or their families.
- the serious lack of any discharge planning that results in patients being sent out into the streets with drugs and the hospital's best wishes.

By 1982, the Ministry of Health had decided to act upon some of the growing criticisms of the mental health system by putting into place the PPAO and Community Advisory Boards (CABs) for each provincial psychiatric hospital. The CABs were seen as a step towards the hospitals being more accountable to the community as well as divesting the Ministry of full responsibility. There is continued speculation, in fact, that CABs may eventually become fully independent hospital boards.

This concept of divesting government and private institutions of services is one that is gaining increased attention. A recent Canadian Mental Health Association (1987) document titled *Community Reinvestment: Balancing the Use of Resources in Support of People With Mental Disabilities* emphasized the need to reallocate resources to the smaller community structures to more effectively address the community needs of psychiatric patients.

The Patient Population

Ontario's ten provincial psychiatric hospitals have treated and discharged an average of 12,500 people each year between 1983 and 1986. While some consumers are affected only temporarily by their disorders, the majority of patients in the provincial institutions are considered to be chronically disabled. Some of these patients remain in hospital long term, while others are part of the "revolving door" syndrome (Dimirsky, 1982). It is well known that these individuals struggle to make it in the community and often have to return to hospital because of inadequate community support and impoverished living conditions. Heseltine (1985), Talbott (1978) and others have presented data to suggest that a very large percentage of people from many of these hospitals could be living in the community if adequate supports were provided.

Legislative Change

Since 1978, the Ministry of Health has embarked on an extensive set of legislative changes in the mental health field. As of 1982, Sections 66 and 67 of the Mental Health Act were designed to expand the rights of psychiatric patients. In December 1986, Bill 7, which legislated a patients right to challenge a finding of mental incompetency to consent to treatment, came into force. Most recently, Bill 190 came into force, amending the Mental Health Act,and thereby enabling mentally competent patients, including involuntary patients, to have an absolute right to refuse treatment. Also, even if mentally incompetent, a patient may now apply to the Review Board for the appointment of a personal representative.

It is important to understand legislative change in the context of this evaluation. As we began the evaluation, it was clear that a 'rights versus treatment' issue was becoming a very strong concern throughout the mental health field. While a number of community groups strongly supported Bill 190, physicians and psychiatrists had lobbied for an amendment which would have maintained the Review

Boards' authority to override a mentally competent patient's decision to refuse treatment. The Ministry had initially supported such an override, but toward the conclusion of this evaluation, the override was withdrawn by the Ministry as the consequence of a strong lobby by consumer and advocacy groups.

Advocacy Ontario

Shortly after this evaluation was initiated, the Attorney General of Ontario announced that a review of advocacy for vulnerable adults would be completed by Father Sean O'Sullivan by July 1987. The review was in response to community groups' and advocacy organizations' increased lobbying of the Government of Ontario to establish a province-wide advocacy program. The intent of Advocacy Ontario would be not only to serve the needs of psychiatric patients, but also to be available to many vulnerable people in a variety of other settings.

Later in this document, we will indicate ways that the future structure of the PPAO can link with broader advocacy systems. In addition, we believe that the empirical data from this study will be useful to new advocacy initiatives in Ontario and other parts of Canada.

Chapter II

METHODOLOGY

In this chapter, we describe our methodology for the evaluation and discuss issues which affected the whole study. The areas which were most crucial to the development and implementation of this study included:

- the use of primarily qualitative rather than quantitative methods.
- the development of appropriate types of methods.
- sampling.
- inherent limitations.
- analysis and interpretation of the information collected.

Each of these areas is briefly described below.

A. PRIMARILY A QUALITATIVE STUDY

Our study design relied primarily on qualitative data obtained through individual and group interviews. Quantitative studies, by way of contrast, essentially measure each evaluation question according to a numerical figure (e.g. percentage of cases successfully completed). While some quantitative data were utilized, most of the evaluation issues required qualitative data which permitted more depth and insight.

Several evaluation researchers have recommended that qualitative approaches be used with programs which have a broad set of aims (Patton, 1978; Stahler and Tash, 1982; Weiss and Rein, 1972). Qualitative interviewing, because of its personal and individualized nature, enabled us to tap people's perceptions, concerns, and knowledge in a comprehensive manner. As Bercovici (1981) has pointed out, qualitative research also takes into account the system and environment of which the individual is a part. Others have suggested that qualitative data are more usable for policy makers because its findings are descriptive and therefore can be more easily applied (Bogden & Taylor, 1975; Weiss, 1972).

Finally, a qualitative approach using interviews was most suitable for many of the patients in this study because of their discomfort with written materials and their concentration difficulties.

B. TYPES OF METHODS

Six methods were used to gather information:

- *documents analysis*: this included an analysis of a variety of reports, statistics, minutes, and briefing notes from the PPAO, Ministry of Health, Advisory Committee, Review Boards, Community Advisory Boards, and hospitals.
- *observation*: site tours of each hospital were done at the end of each visit. Wards, program areas, and the advocate office were observed in action.
- *interviewing*: interview guides, which reflected the research questions and design, were used for individual and group interviews; most questions were open-ended.
- *knowledge survey and staff questionnaire*: a brief survey of eight questions regarding specific legal and human rights was used with all staff, except the administrator, and patients. In addition, a series of closed and open-ended questions concerning knowledge of the PPAO and perceptions of impact and benefits were used for staff only.
- *submissions*: a newspaper advertisement was published in major newspapers, including all centres where provincial psychiatric hospitals are located, to solicit submissions from individuals and groups wishing to have input into the evaluation; approximately 100 submissions were received throughout the duration of the study. The purpose of the submissions was to guide the researchers in the evaluation process and to contribute to the data base.
- *community meetings*: in each of the 10 communities with a psychiatric hospital, community meetings were held. These meetings had two components: a formal group interview, chaired by the researchers, and an open-ended discussion and feedback session, chaired by the chairperson of the Evaluation Committee.

C. SAMPLING

A credible review of a program which affects so many people requires that every stakeholder or group with an interest in the issues be included (Stahler & Tash, 1982).

We visited all ten provincial psychiatric hospitals in order to assess differences in advocates' approaches, geographic locations, staff attitudes, and patient populations. By visiting each hospital, the study's validity and reliability were improved and the opportunity to generalize from the findings was increased.

Two researchers visited each hospital for approximately three days, during which time data were gathered from staff, patients, families, administration, the advocate, and the rights advisor. Community members were interviewed at an evening meeting held in the community.

Patients

We sampled 15 patients from each hospital. Prior to a site visit, the advocate office in the hospital was asked to provide the researchers with a list of all cases on which they had worked in the last 30 days. (See the form used in Appendix B). The form completed by the advocates identified each client's age, sex, duration of latest hospitalization, type of case (legal, therapeutic, social), status on admission and current status (voluntary/ involuntary) and whether the case was closed, open, or pending closure. The lists identified patients only according to a case number.

From this information, the researchers randomly selected patients from four categories: 4 patients whose cases were legal, 4 therapeutic, and 4 social. In respecting confidentiality, the patients who were invited to participate in interviews were handed a letter by the rights advisor 48-72 hours before the interview. The letter explained the purpose of the interview and the study and asked the patient if s/he would like to participate voluntarily.

Three group interviews and 3 individual interviews were held at each hospital site. In addition, 3 non-clients of the PPAO were randomly selected from the rights advisor's list. Finally, the case of one patient who had been identified as a non-instructed case was selected and investigated.

Staff

The hospital administrator's office was asked to submit a list of staff who were working on the days of the researchers' visit. In each hospital, staff were selected from this list using a stratified random sample, with most staff being selected from wards where there was a high degree of advocate activity. Interviews lasted 1 to 1 1/2 hours.

- The administrator was interviewed separately, as was the medical director/psychiatrist-in-chief. A group interview was held with 4-5 psychiatrists.
- The director of nursing was interviewed separately; one group interview was done with nursing supervisors; and one group interview was done with floor nurses.
- One group interview was held with 4 social workers. As well, an informal meeting with union representatives was held in several sites.

Advocates and Rights Advisors

Interviews with advocates lasted 4 hours (in 2 parts). Interviews with the rights advisors took approximately 1.5 hours.

Others

Families. Each advocate office was asked to submit a list of families who had had contact with the Advocate Office in the last 30 days. After the researchers randomly selected 3 families, advocates phoned the families and asked them if they would be willing to be contacted by the researchers and interviewed. Telephone interviews were then conducted when the researcher was in town, at the time specified by each family.

Regional Review Boards and Community Advisory Boards. Representatives from each Board were asked to meet with the researchers at the hospital. In some cases the interview was with the chairperson and at other times with members of the boards, depending on their availability.

Community Meetings. The local branch of the CMHA was asked to organize the community meeting. A letter from the researchers was sent by the CMHA to a number of former patients, families, associations and community agencies. In addition, the Advocate Office was asked to send letters to former clients inviting them to the community meeting. Thus, participants in the community meetings were not randomly selected. On the average 8 to 15 people attended each meeting, except in Toronto where two meetings were held; 25 people attended a meeting for agency and association people, and another 16 attended a separate meeting for former patients.

Central Interviews. Four staff members from the central office of the PPAO were interviewed, including the current and former Provincial Co-ordinators.

The advisory committee of the PPAO was interviewed as a group. In addition, two officials from the Ministry of Health, who have had primary responsibility for the PPAO program, were interviewed separately. A summary of the total number of people interviewed can be found in Table 1 below.

Table 1
Total Interviews

Patients	108
Advocates	12
PPAO office	4
Administrators	10
Ministry of Health (Toronto)	2
Rights advisors	10
Psychiatrists/physicians	49
Nurses and registered nursing assistants	96
Social workers	44
Family members (1 from each family)	20
Participants at community meetings (an approximate total of the 11 meetings)	130
Members of Regional Review Boards	17
Members of Community Advisory Boards	18
PPAO Advisory Committee	7

D. LIMITATIONS

All research designs have intrinsic limitations (Campbell and Stanley, 1967). In designing this evaluation, we identified the limitations of our study and built safeguards into the research methodology to ensure that any potential for bias would be kept at a minimum. Below are the limitations and safeguards which emerged from this study:

1. *Logistical problems*: a few families were not available for their phone interviews. Some patients did not show for their interviews for a variety of reasons: fear at the last moment, discharge, unavailability due to other programming. A small number of staff refused to be interviewed or had their shifts changed. Some interviews with patients

were difficult to conduct because of the respondents' lack of focus or clarity at the time of the interview.

Safeguards: a large sample size was chosen initially to ensure adequate representation of the groups interviewed. When possible, we replaced people who did not appear for the interview with a randomly selected back-up participant from the original population.

2. *Recollection*: the interviews were based primarily upon what people could accurately recall from their past experiences with the advocate office.

   Safeguards: the sample consisted of people who had recent experiences with the advocate, as well as people who had had time to reflect back on their experiences, even though they might not have been able to recall the finer details. Former patients at community meetings also provided more reflective insights.

3. *Perception versus reality*: this study is based primarily on people's perceptions. Perceptions and reality are not necessarily congruent.

   Safeguards: in order to counter any potential distortion, we consistently asked people to support their statements with concrete examples. Nevertheless, we also recognized that what some people offered as perceptions also represented their view of reality. These multiple views of reality enabled us to create a more comprehensive understanding of the opinions of the various participants.

4. *Articulate can dominate*: it is possible that more articulate persons can be over-represented in data analysis and presentation (Miles and Huberman, 1984).

   Safeguards: we sampled proportionately more patients to ensure that their views were well represented. In group interviews, we encouraged less vocal individuals to speak out; and the submissions process provided another avenue for people to express their views. Throughout group interviews and analysis we were careful to note majority and minority views.

5. *Tendency to generalize*: in qualitative research, there is a danger of fitting events into general patterns without adequately allowing for the exceptions and differences (Miles and Huberman, 1984).

Safeguards: Again, minority views have been noted throughout. Random sampling also helped to ensure a range of perspectives. As well, the methods used for analyzing the data were designed to capture details and differences.

6. *Effect of site on the researcher*: in field research, there is a danger that the researcher can be overly influenced by the environment and accept the local, agreed-upon version of events.

   Safeguards: Spending 3 days on each site allowed the researchers time to observe and formulate their own sense of the environment without being co-opted by the institutional culture and predominant opinions of staff.

E. DATA ANALYSIS

An extensive amount of information was gathered at each site. The data were then combined to illustrate a total perspective of the PPAO. A cross site analysis was done. Where differences between sites illuminated important issues, distinctions and comparisons were made with the other sites.

Like most qualitative studies, this evaluation did not begin with a theory or hypothesis to test. Rather, in the tradition of grounded theory (Glaser and Strauss, 1967), experiences, perceptions, and processes were analyzed to identify patterns, themes, and nuances of understanding. This process of inductive analysis produced patterns and themes in two ways. Some emerged directly from the participants, while others were noted by the researchers (Patton, 1980). As we shall see, with some issues that emerged in this study, the focus on individual perceptions created a sense of "multiple realities" (Wiseman, 1970).

The six steps of the qualitative analysis included:

1. *Organizing* notes from the interviews and the field with detailed quotations and observations. Immediately after each interview, the researchers reviewed their notes, highlighting direct quotations and tidying up the interview notes. Brief field notes based on the researchers' observations during the interview were made.

2. *Summarizing* the data from each site according to sectors. For example, the individual and group patient interviews

would be summarized according to the research questions. Summaries included the number of patients who expressed a particular viewpoint with accompanying quotations and summary comments.

3. *Coding* the data by sector (e.g. advocates, nurses etc.). This was done by combining the data from all sites. For example, summaries of social workers from all ten sites were combined, then coded as a total group.Coding is a process of attaching key words or phrases to interview data as a way of identifying commonalities and variations in the data. Researchers met to establish common codes across sectors.

4. *Identifying* common and variable patterns by sectors. This was done after all data was coded. Based on the codes, common patterns or findings were developed for each sector according to each research question. These common patterns or majority views were noted. At this stage, other variable patterns or minority views on the same patterns were also identified.

5. *Comparing* patterns across sectors. This was completed after patterns were identified for each sector. For example, patient data on the advocacy process were compared with staff data on the advocacy process. This showed that patients were generally content with the process, whereas staff had more varied responses.

6. *Identifying* themes which link or explain the data. For example, the "style of the advocate" explains some of the process data and "rights versus treatment" explains some of the impact data. Themes, in many ways, are overriding issues which emerge from the inductive analysis process.

This six step inductive process is consistent with the most rigorous and valid research approaches (Miles and Huberman, 1984; Patton, 1980). At the same time, this approach produces readable and useful material in descriptive terms.

Chapter III

EFFECTIVENESS:

OF PATIENT INSTRUCTED ADVOCACY PROCESS

In this chapter, we shall present data on how well and to what degree the objectives and mandate of the PPAO have been met by the individual advocacy processes. In developing a comprehensive analysis of effectiveness, we have organized our data according to the following research questions:

- How well informed are people about their civil and legal rights and about the PPAO program?
- What types of processes are used by advocates with patient-instructed case advocacy and how effective are these processes?
- What are the main variations in the individual casework advocacy process and how effective are they?
- How satisfied or dissatisfied are patients and staff with the advocacy process?

In this first chapter on Effectiveness, we focus on patient instructed advocacy, which refers to situations where patients have given the advocate general or specific instructions to fulfill. This is in contrast to non-instructed cases and systemic advocacy, which will be discussed in the next chapter.

A. INFORMING PEOPLE ABOUT RIGHTS AND ADVOCACY

One of the goals of the PPAO is to "advance the human rights of psychiatric patients in all Provincial Psychiatric Hospitals." A second goal emphasizes that advocates should, "inform the patient, family, hospital staff and community about patients' human and legal rights" (PPAO, 1984).

A variety of methods were used to determine whether or not people were informed about the civil and legal rights of psychiatric patients and the extent to which people know about the Psychiatric Patient Advocate Office. Staff, patients, and advocates were asked about methods of informing and the effectiveness of this educational process. In addition, all staff members were asked, by way of a written survey, to evaluate the type of information which they received from the advocate.

Methods Used by Advocates to Inform Patients and Staff

All advocates employed a variety of means to communicate information about the advocacy program and about civil and legal rights. The primary methods used by advocates were:

- posters and booklets throughout the hospital and at the Advocate Office (these materials had been prepared by the PPAO and the Ministry).
- speaking to patients or staff members individually; formally or informally.
- speaking to groups of patients, staff, and community groups.
- rights advisors giving information to involuntary patients.

The comment of one advocate reflected the importance of having a number of different approaches:

> *"Since no one method is going to reach any one group, we use the pepper method."*

On the wards, all advocates displayed PPAO posters that informed patients and staff about the advocate office.

Although the rights advisors saw only a small number of people who came into the hospital, their role was important for involuntary patients. Since March 1986, all involuntary patients have had to be seen by the rights advisor within 48 hours after committal. At several sites, the Patients' Rights Booklet, a PPAO brochure, and a card with the advocate's name and number were given out by the rights advisor.

Five of the advocates emphasized that their preferred method of communication was speaking to patients or staff individually. This was either a formal or informal process, depending on the style of the advocate. One advocate, for example, found it particularly helpful to spend time on each ward, meeting with head nurses and "just being there." Some advocates emphasized that they felt most comfortable informing people on a one-to-one basis so that they could individualize their approach.

All advocates spoke to groups of patients, staff, and to community groups. Some advocates emphasized the importance of this activity in furthering the PPAO goal of informing people about civil and legal rights and as part of a general information sharing process.

> *"I spend a lot of time with staff, especially around orientation as well as having informal discussions. I find that the nurses especially appreciate the seminars where we can discuss the philosophical issues."*

Other advocates noted that they sometimes presented information about the PPAO at unit meetings or, when invited, were involved in ward meetings of patients.

The process of individual and group education seemed to be somewhat sporadic. Only three advocates indicated that they conducted educational seminars and information sharing in an ongoing and systematic manner. These particular advocates utilized some very creative methods, including the development of a video tape, the use of envelopes for patients so that they can send requests for information through the internal mail, and the distribution of articles and other reading materials to staff.

All advocates spoke to community groups from time to time to inform their communities about rights and advocacy. The advocates generally agreed that:

> *"Community education is important because there are many misconceptions about mental health and advocacy."*

In order to assess the effectiveness of these methods of information dissemination, we examined the degree to which patients, staff, and families were knowledgeable about civil and legal rights, and the extent to which they knew about the PPAO.

Patients' Awareness of the PPAO

Most patients at all hospitals mentioned posters and other information on the wards as the main vehicle for learning about the PPAO and rights. One patient expressed it most clearly:

> *"The posters are good; they tell you what you need when you first arrive."*

For a minority of patients, however, this form of information sharing was not effective, either because of illiteracy, language barriers or confusion. One patient noted:

> *"They gave me something, but I can't read."*

In all but one hospital, the patient advocate and the rights advisor were mentioned as another main source of information. At half the hospitals, patients emphasized that the advocate "comes to the ward and talks to the patients."

The other most frequently mentioned sources of information were staff, friends and relatives, and the PPAO blue booklet on patients' rights.

In almost all the hospitals, there was a small number of individuals who appeared to have little or no knowledge of the PPAO. Sometimes their vagueness appeared to be a function of *when* they received information rather than what they received. Several people expressed concern about the timing of the visits from the rights advisor.

> *"I was too upset and too tired when I came in. They should come and talk about rights when you feel better."*
>
> *"Someone came to see me. I can't remember what they told me."*

Of those patients who were able to articulate the role of the Advocate Office, a number of recurring perceptions were identified. These patients tended to emphasize that the mandate was:

- to support and represent patients by hearing their concerns, dealing with their complaints, answering their questions and doing background work.

- to protect rights by being an independent voice.

- to act as a mediator and liaison between patients and staff.

Most patients were clear that the role of the Advocate Office was to work on their behalf:

> *"A place where you can appeal for help in what you want."*
>
> *"They listen to the people, help them better their rights. Advocates give advice and support. "*

> *"The advocate helps with any problem with staff and deals with all aspects of patients' problems."*

Non-clients whom we interviewed were far less knowledgeable about the PPAO and about their rights than those who had used the office. About one third of the non-clients were unable to say anything about the role of the advocate office:

> *"I don't know anything about it."*

Several non-clients had at least a vague understanding of the role of the PPAO, and a few of them actually seemed very well informed.

In speculating on why so many non-clients knew little about the office, the researchers noted that the PPAO posters were not visible on all wards. Also, since most people who had not used the advocate had not visited the Advocate Office, they were less likely to have picked up written materials.

Patients' Knowledge of Rights

Patients who had used the advocate office, then, were clearly more knowledgeable about the mandate and goals of that office than were patients who had never been clients of the PPAO. In addition, patients who had used the PPAO were more knowledgeable about their rights. Table 2 demonstrates that civil or human rights, such as the right to untampered mail, were mentioned frequently by the patients. The other rights often mentioned were procedural, such as the right to obtain a lawyer.

Table 2

Rights Mentioned Most Often by Patients

Right	No. of hospitals
Right to freedom and privacy, e.g. phone calls, going outside, smoking, untampered mail, having money	11
Right to go to Review Board, appeal certification	8
Right to obtain counsel - legal aid, lawyer, advocate, minister	7
Right to refuse treatment/medication	6

Most patients made a distinction between what rights they had and their ability to enforce them. One patient noted:

> *"You have the right to refuse treatment or to refuse medication, but if you do, staff will often coerce you or say 'you'll stay here forever' ."*

In every site, there was a minority of people who demonstrated a poor understanding of rights. Some patients were quite direct:

> *"I don't know anything about patient rights - don't know if we have any rights or not."*

> *"The staff shouldn't be able to refuse you anything; if you need clean clothes you should be able to get them without waiting."*

Another patient reflected the feelings of a small minority of patients who were seeking more information:

> *"We need more information that we have I thought we didn't have any rights; I need to know... how do I find out?"*

Staff Perceptions of PPAO Methods of Informing

The staff survey indicated that a variety of perceptions of the informing process exists among staff. Some of these perceptions concern the manner in which the information was communicated and the effectiveness of this particular style of communication (see Table 3). More than half the staff (52.8%) were aware of educational activities undertaken by the PPAO in their hospital. Staff felt much more positive than negative about access to PPAO information and the usefulness of that information (see last four items in table).

Staff who noted that the information from the PPAO was not useful (21%), tended to emphasize that:

> *"It has nothing to do with treating the patient; it's more useful to social workers."* *(psychiatrist)*

In a separate analysis, when hospitals were compared, it was interesting to note that four sites stand out as being particularly educational. At these sites, more than 85 per cent of staff were aware of the educational programs and the initiatives from the advocates in contrast to only 52.8 per cent when all sites were combined (see Table 3). In addition, more than 75 per cent of staff at these sites found the information to be useful, in contrast to 44 per cent when all sites were combined (see Table 3). Three of these four "educational" sites were also mentioned earlier in terms of advocates making a special effort to educate staff and patients about rights and the advocacy program. It is especially interesting that only 5.5 per cent of staff at Oak Ridge indicated awareness of educational programs. Perhaps this is partially reflective of the dynamics at Oak Ridge.

Table 3

Staff Perceptions of the Informing Process

Patient Advocate Office had undertaken educational activities to keep staff informed about the human and legal rights of patients	52.8%
Advocates did not undertake such activity	40.8%
Staff indicated knowledge of brochures about the program	32.0%
Staff noted distribution of brochures and information on patients rights	39.0%
Staff had participated in some in-service seminar or formal talk with the patient advocate or PPAO	32.0%
Staff indicated that information was easy to obtain	57.8 %
Staff indicated information was quite difficult to obtain	15.7%
PPAO information was quite useful	44.0%
PPAO information was not useful	21.0%

Degree to Which Staff are Knowledgeable About Mandate of PPAO

The majority of staff had only general to limited knowledge about the advocate's mandate. Staff knowledge and awareness about the mandate of the PPAO fell into three areas. First, they saw the advocates as protectors of rights. A nurse's comment was typical:

> *"The advocate ensures that rights are not being violated, and if they are, to step in and act on behalf of the patients."*

The second area that staff saw in the advocate's mandate was to act on the patients' behalf in an objective manner. A psychiatrist emphasized this point:

> *"The advocate makes himself available as someone who is impartial...to respond to patients' best interests and concerns."*

The third aspect of the mandate which was mentioned most often was that the Advocate Office provided an information source for patients' rights. At six sites, staff also saw the advocate as being an information source for staff.

> *"The advocate ensures that rights are kept in line. They answer our questions regarding stay in hospital, they direct patients to the services needed."*

Psychiatrists were often not as well informed as the other professional groups. At three sites, for example, almost all psychiatrists lacked concrete information about the mandate of the PPAO. The comments of two psychiatrists represent this perspective:

> *"I have no idea about the mandate, I never knew why it was set up, or for how long."*

> *"I am not sure either they or I know the breadth of their mandate."*

One psychiatrist explained his colleagues' lack of knowledge with the observation that there has been "little direct communication between patient advocates and psychiatrists." This is supported partially by the fact that psychiatrists were more negative at those sites which were considered less educational according to our previous data. While this may be a partial explanation at some of these sites, it appears that a minority of psychiatrists, by their tone and emphasis, were also resistant to accepting the PPAO mandate. At one site, for example, four psychiatrists in a group interview could not describe the mandate or purpose of the Advocate Office in their hospital, but instead emphasized perceived negative attributes such as:

> *"Doctors have to be watched and the advocate basically works against the patients' best interest."*

Knowledge Survey

In addition to the questionnaire survey and indepth interviewing process, patients and staff at all hospitals were given a knowledge survey (Appendix C). The survey consisted of seven statements regarding patients' rights. The knowledge survey was developed by the research team in consultation with several human rights lawyers and was based upon rights mentioned in the Mental Health Act of Ontario.

Respondents were asked to indicate whether each statement was true or false. The purpose of the knowledge survey was to determine the extent to which patients and staff were knowledgeable about the rights of mental patients in psychiatric hospitals.

The findings from the knowledge survey included:

- Staff were able to answer 73.3 per cent of the questions on rights correctly, while patients were able to answer 63.25 per cent correctly. These findings are somewhat higher than a knowledge survey used in American psychiatric hospitals (Laves & Cohen, 1973).

- There were two questions that were most difficult for staff and patients. When they were eliminated, patients' correct answers actually increased to a level (78 per cent) higher than the staff's (75 per cent).

  One of the questions, which patients and staff found difficult, related to whether people could interfere with mail being sent to and from a patient. Sixty-nine per cent of staff and 78 per cent of patients noted that mail sent to and from a patient could not be subjected to interference. In answering this question, several patients indicated that they wished that was their right but that staff *regularly* interfered with their mail. According to the Mental Health Act, mail can be interfered with under certain circumstances. The large number of erroneous answers to this question tended to confirm our earlier finding which was that patients' and staff's perceptions of rights were often clouded between what they thought were rights and what was actually happening in the hospital.

  The other question which many staff and patients were confused about was related to whether or not patients can have a copy of their clinical record if they request it. While the answer is "yes," there are procedures which must be followed and the physician is able to keep certain data, which might be injurious to the person, out of the file. The confusion and comments around this question, probably typified the general confusion in the mental health system about this particular issue.

Community Perceptions

Community meetings in each hospital community gave the researchers an opportunity to determine how well known the

Advocate Office was and also to better appreciate the degree to which people understood the mandate of the program.

It appeared that the PPAO was not well known in the community in general, but was reasonably well known by those agencies that were associated with mental health and the psychiatric hospitals:

> *"The program is well known with agencies hooked into the hospital like CMHA, but not with other agencies like Welfare."*
>
> *"From what I hear the Patient Advocate Office has no standing in this community whatsoever."*
>
> *"The PPAO does not appear to have a very public presence in the community. Their profile is highest among former patients."*

Although community agencies seemed to know about the PPAO's existence, there was a wide variety of perceptions of its mandate. A majority of people had some knowledge, but only a minority of people seemed to have a clear sense of what the PPAO was designed to achieve. A minority based their view primarily on hearsay. The community people who were clear as to the advocates' mandate represented various sectors including patients, community agency people, and family members.

> *"Advocates speak out for others. Their role generally involves assisting others to put forward their views and to gain their rights."*

The ability of community members to be articulate about the PPAO mandate seemed to be directly related to the closeness of their actual contact with the office. Many community people who had no contact with the PPAO often described the mandate in a very narrow way.

> *"The advocates don't have much authority... they tend to listen to the staff."*
>
> *"They have authority to do whatever they want."*

Several community people, including former patients and voluntary agencies, had some thoughtful comments about the role and mandate of the Advocate Office:

> *"I would say there is a lot of confusion about the difference between advocacy and case management, and discharge planning and therapeutic intervention. I think certainly*

> *through the work that I have done on community committees, that there is no agreement where advocacy starts or where case management begins."*

Several former patients were extremely articulate about the role and mandate which should be emphasized for the PPAO.

> *"What about access to people who are mobility impaired? What about people who do not have privileges to get off the ward? What about people who do not speak English? What about those who do not read or write any language? The advocate's mandate needs to be proactive as well as reactive to the folks who can get to their office."*

The community data, while somewhat sketchy on this issue, did suggest that the PPAO probably needs to take a closer look at the ways in which it informs people about its programs and services.

Summary

Our data suggest that advocates have only been partially effective in meeting the PPAO goal of informing people about rights and the PPAO. While patients and advocates mentioned a variety of educational methods used in the informing process, these methods were clearly most effective with literate patients who have been PPAO clients. Non-clients of the PPAO were the least informed group of respondents.

Staff knowledge of the advocate office and mandate was not extensive. It varied among professional groups, with psychiatrists being the least well informed. At the same time, however, three sites were particularly "educational", and advocates at those hospitals had developed fairly systematic approaches to staff education. Staff at these sites indicated a much higher awareness of educational initiatives by advocates than staff at other sites.

B . THE BASIC CASEWORK PROCESS

In this section, the general process followed by advocates in doing their casework is presented (see Table 4). While few advocates actually identified all six steps, this description of the process evolved from compiling the information gathered from all advocates. Variations to this process are described in the next section. The six steps in the process of individual advocacy are each briefly outlined below.

Patient Contact

The advocacy process for individual cases begins with patient contact with the advocate. Referral sources for the past three years are shown in Table 5. Over 70 per cent of patients were self-referred. Patients referred by all categories of hospital staff accounted for an additional 20 per cent of referrals.

In most cases, the patient walks into the advocate office. In some cases, when the patient is on a closed ward, the patient phones for an appointment. When there is no telephone access, the patient must ask staff to call for an appointment. Advocates also make appointments for patients, and see patients personally while on the ward.

Initial Meeting

The purpose of the initial meeting between the advocate and the patient is to clearly identify the patient's problem(s) or complaint(s), discuss actions that may be taken, and receive instructions from the patient.

In most cases, patients clearly state their problem and instruct the advocate. In the simplest case, this might be "I need a lawyer because...". The advocate can proceed directly and act upon the patient's instructions.

In some cases, the instructions are clear but impossible to fulfill, for example, a patient on a Lieutenant-Governor's Warrant who wants an immediate discharge. In rare cases, the advocate has to refuse to take the case. Most often, instructions can be negotiated. By uncovering the reasons that the patient seeks discharge or change of ward, the advocate may be able to act on these underlying problems instead of the less realistic instruction initially presented.

The process of problem identification and receiving instructions is not simple. For a variety of reasons (including acuteness of illness, medication, etc.), a patient may not be able to clearly describe his or her problem, let alone instruct the advocate. Most advocates reported that in these cases they they make further appointments with the patient, until the patient is capable of clarifying the problem and giving instructions. If the problem appears critical and instructions can not be given, the advocate may pursue the case as a non-instructed case (see Chapter IV). In a few cases, when the patient is deemed incompetent to instruct, substitute consent may be sought from a person named by the patient. Recent legislation amending the Mental Health Act (Bill 190) enables patients who are deemed incompetent to name a substitute decision maker to speak and exercise choices on their behalf.

Table 4

Basic Casework Process

(As Described by Advocates)

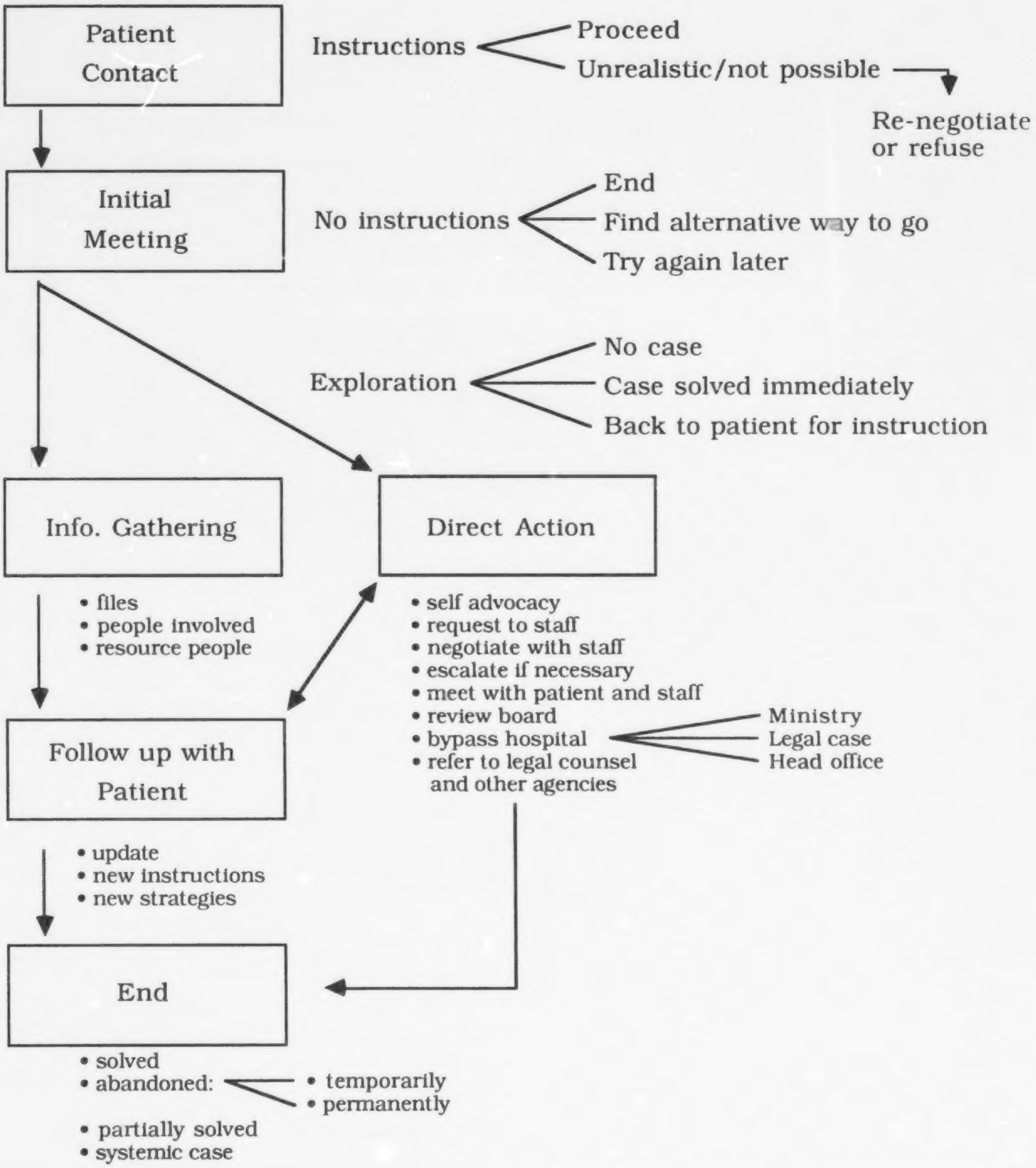

Patient Contact
Instructions
Proceed
Unrealistic/not possible
Re-negotiate or refuse
Initial Meeting
No instructions
End
Find alternative way to go
Try again later
Exploration
No case
Case solved immediately
Back to patient for instruction
Info. Gathering
• files
• people involved
• resource people
Direct Action
• self advocacy
• request to staff
• negotiate with staff
• escalate if necessary
• meet with patient and staff
• review board
• bypass hospital
Ministry
Legal case
Head office
• refer to legal counsel and other agencies
Follow up with Patient
• update
• new instructions
• new strategies
End
• solved
• abandoned:
• temporarily
• permanently
• partially solved
• systemic case

Table 5

SOURCES OF REFERRALS TO ADVOCATES

Sources	1983/84		1984/85		1985/86	
	n	%	n	%	n	%
Self-referred	1,515	68	1,968	74	1,772	69
Family	39	2	46	2	59	2
Friend	11	1	113	4	24	1
Other patient	39	2	14	1	23	1
Other client	4	0	8	0	30	1
Nursing staff	181	8	133	5	165	6
Physician	45	2	65	2	52	2
Psychologist	3	0	9	0	16	1
Social worker	41	2	51	2	72	3
Within PPAO	207	9	144	5	161	6
Other clinical staff	15	1	12	0	23	1
Non-clinical staff	32	1	13	0	27	1
Administration	8	0	19	1	11	0
Review Board	9	0	3	0	1	0
Advisory Review Board	0	0	2	0	6	0
External agencies or individuals	74	3	80	3	58	2
Records	-	-	0	0	4	0
Not recorded	-	-	74	3	77	3
TOTAL REFERRALS	2,223		2,654		2,581	

Source: PPAO data

In some cases, the exact nature of the patient complaint is unclear. This is often true when two or more related issues are presented to the advocate or when the problem concerns events on the ward. The advocate may explore the issue(s), seeking clarification of the problem(s). Sometimes, in the course of exploration, the problem is solved. In other cases, the advocate is able to clarify the problem and return to the patient for appropriate instructions.

Confidentiality is a critical component of the relationship the advocate establishes with his or her client. The importance of confidentiality was outlined in the 1984 PPAO Policy and Procedural Guidelines:

> Once an advocate has taken instructions from a patient, a confidential relationship is formed whereby the advocate is committed to keep secret everything concerning the client's situation, including who the client is, without explicit consent from the client. The advocate is under a duty not to divulge confidential information and that duty extends so far as to include the fact of whether or not the patient has even consulted him.

In sum, during the initial meeting with the patient, advocates make every effort to understand the problem presented by the patient, to receive instructions from the patient regarding actions the advocate should take, to clarify the client's wishes around confidentiality, and to identify one or more strategies for acting on that problem. If it appears that the case is going to proceed, the advocate normally opens a file for the person and identifies one or more strategies for acting on the problem.

Information Gathering

Usually, the advocate will need more information in order to deal with the patient's instructions. The advocate may access files and hospital policies, observe on the ward, discuss the problem with staff or others involved, and/or contact outside resource people. The extent to which the advocate discusses the complaint with staff and others will vary depending on the decisions that have been made with the client around confidentiality and the personal style of the advocate. The results of these activities are usually conveyed to the patient so that strategies can be chosen and instructions can be updated.

Direct Action

As noted in Table 4, the actions or strategies employed by an advocate are quite varied, depending on the type of case and the context or environment. Communication may involve memos and/or letters, or may be accomplished in person.

The problem-solving strategies available to the advocate relate to the type of issue presented by the client. As presented in Chapter 1, the PPAO categorizes issues in four ways:

- Quality of Life or Social Advocacy Issues
- Quality of Care or Therapeutic Advocacy Issues
- Self-determination or Legal Advocacy Issues
- Other, including information requests and complex cases not fitting into a single category.

Table 6 shows the number and percentage of each type of issue during the initial three years of the program. Each year, the number of social and therapeutic issues has been roughly equal to the number of legal issues presented. Legal issues are most likely to be referred to community lawyers. The other half of the typical caseload, social and therapeutic cases, tends to be more time-consuming and requires various personal skills on the part of the advocate. These cases provide the strongest rationale for having an advocate on site, in the hospital, and accessible to clients and staff.

The simplest form of action is a legal referral. In cases dealing with legal issues (e.g., referrals to the Regional Review Board or the private bar), advocates assist with the referral and with arrangements for appropriate documentation. Other "easy" cases involve responding to requests for information, or requests for things that are generally accepted as entitlements (e.g., glasses, dental care, etc.).

Cases are considered difficult for two reasons. First, the more people who have to get involved and the further the issue gets from the advocate or the ward, the harder the cases are to solve.

> *"It's more complicated and it takes longer when you need 3 or 4 people and an external agency,or when you have no control over what the patients' needs are such as in housing."*

Secondly, advocates consider treatment issues to be more difficult to handle primarily because of staff resistance.

> *"Therapeutic issues are seen by professional staff as interfering with treatment - they are resistant."*

Table 6
Types of Issues in Files Closed by the PPAO Annually
1983 - 1986

	1983/84		1984/85		1985/86	
Type of Issue	n	%	n	%	n	%
Therapeutic	1016	18	1,369	21	1,394	18
Social	1464	26	1,698	26	1,928	26
Legal	2336	41	2,772	43	3,518	47
Other	820	15	674	10	704	9
Total	5636	100	6,513	100	7,544	100

* 1983/84 data were collected for 3 months only. The above figures represented an extrapolation of the 3 month figures.

> *"This [therapeutic] is the area where the best interest model and the self directing model come into conflict. Doctors feel their competence is being questioned."*

Sometimes discussing the problem directly with staff and proposing a course of action solves the problem. This is especially the case when staff are not aware of the problem and have a good relationship with the advocate. In other cases, a negotiated solution is possible. This may be accomplished quickly or may take many months to achieve.

Negotiating. Most advocates begin problem-solving at the lowest appropriate level of the institution and escalate the case through higher levels of authority as necessary. A few advocates, as we shall see later, begin their strategy with a higher level of authority. In some cases, this is necessary. If a matter is perceived as very serious or urgent, an advocate may bypass the hospital entirely by going directly to the Ministry or by referring the case to outside counsel. In some cases, patient direction requires the advocate to follow a course the advocate would not necessarily see as most desirable, i.e., escalating too quickly.

There are no clear PPAO guidelines regarding when and how to escalate a case. However, Head Office has recently initiated a pilot study in which advocates and Head Office staff are documenting the advocacy process.

Self-Advocacy. Advocates often propose self advocacy as a first step, especially regarding treatment or medication issues. The patient is encouraged to discuss the issue with the physician or nurse involved and is helped to formulate the issue, clarify the problem, and decide what questions to ask. The theory is that patients will learn to advocate on their own behalf and that this will transfer to other situations that the patient finds him or herself in, thereby lessening dependence on the advocate and promoting autonomy. As one advocate pointed out:

> *"I don't practise advocacy in isolation from the client, unless they demand it. The person is encouraged to resolve it at a more basic level first. For example, I might say: 'Have you talked with so and so first? Why don't you have a shot at it and let me know how it goes."*

Patients who appear to be able and agreeable are encouraged to discuss treatment issues with their physician and return to the advocate if the outcome is not satisfactory to the patient. When the patient seems unable to act alone, a meeting may be arranged with staff, patient, and advocate. Depending on the situation, the advocates play a variety of roles at such meetings. Sometimes they simply observe and silently support the patient; other times they act as a clarifier of the problem; sometimes they propose various solutions previously discussed with, and acceptable to, the patient; and at other times they actively represent the patient.

Follow-up with the Patient

Advocates are responsible primarily to the patient or client. Accordingly, they may seek out the patient to update information or revise a strategy. Some patients will drop into the office regularly to follow their case. Otherwise follow-up activities may occur on a casual basis in the halls, grounds, or wards.

End of Case

The advocate records details of the case to a greater or lesser degree, depending on the nature of the outcome of the case. If there is no further contact with the client, the client file is closed 30 days later and the case is concluded. The advocate also makes a judgement about whether or not patient instructions were fulfilled and sends statistical reports concerning these judgements to the Head Office.

A Case Study

The following case study illustrates many of the process steps that were outlined in Table 4. The advocate discussed with the patient the right to refuse treatment and talked with the doctor about the meaning and importance of informed consent. The advocate also provided the client with information on the drug in question to assist the patient in making an informed decision. What this case lacks, however, is a clear statement on the outcome.

A 34 year old male advised the advocate that his medication Trilafon had been discontinued three days earlier and he had been placed on Haldol with no discussion by the doctor of this change in medication. The patient wanted to have the Haldol discontinued and was willing to discuss other options. He gave permission for the advocate to check his file and speak to the doctor.

In gathering information, the advocate discovered that the medication record confirmed that Trilafon liquid 8 mg four times a day had been discontinued, and Haldol 10 mg morning and night was ordered for one week.

The advocate then raised the client's concern with the doctor emphasizing the doctor's obligation to discuss medication changes with the client. The advocate suggested to the doctor that an opportunity should be provided for the client to receive information on the new drug and to give informed consent to treatment. During this discussion, the doctor offered no explanation for the change of medication or for his failure to discuss the change with the patient. He stated that the client knew he could refuse the medication. The doctor indicated he was unwilling to make any change or enter into a discussion with the client since the patient's regular attending physician would be returning from vacation on Monday. He asserted he had no objection to the advocate providing information on Haldol to the client in order for the client to consent or refuse during the interim.

The advocate reported to the client the doctor's refusal to change the order and discussed with the client his right to refuse or consent over the weekend. The advocate obtained information on Haldol for the client and promised to speak with his attending physician early on Monday to have him review the treatment and discuss the client's preferences.

The advocate spoke to the doctor on Monday, and the doctor promised to see the client as soon as possible. A few days later the client reported he had received good information and was well satisfied with the outcome although he did not elaborate on what changes, if any, had been made in his treatment regime.

Summary

The steps in the advocacy process described above provide a sense of the overall approach taken by advocates with patient-instructed advocacy. Some advocates were much more thorough in their description of the process than others. The steps described above, as well as the variations outlined in the following section, should help these advocates become more conscious of the processes which they utilize in their work. Such awareness will likely increase their individual effectiveness as advocates, and will promote inquiry and criticism which can improve the general process.

C. VARIATIONS IN THE PROCESS

The purpose of this section is to highlight the variations in the case work process as described by advocates.

Documentation and Recording

Paper Work. There are no program guidelines for advocates regarding what and how much should be written down or in what form. In the absence of guidelines, we found wide variability in what was recorded by advocates. Some advocates conscientiously opened a file for each patient with whom they had contact. Others, when the case involved sharing information quickly, did not open a file. Some advocates always began by writing down a statement of the presenting problem; others did not record the initial problems until later in the process; and some made no note of the presenting problem. Some of the advocates required the patient to read and sign a "contract" including a statement of the problem, and a description of the action to be taken.

Comments by advocates indicated that case files varied widely in format and content.

> *"My files are anecdotal. I'm fairly compulsive and detailed."*
>
> *"I write files so that clients can read them. It's useful sometimes to review their case with them. I guess that is my professional training."*
>
> *"I write down as little as possible. Sometimes I don't even open a file. I find that copies of correspondence gives me enough recall on a case. I don't want to get caught up in paper requirements like staff are."*

In one hospital, the rights advisor and the advocate opened one shared patient file. This arrangement seemed more useful to them than having two separate files on the same patient.

In terms of how advocates communicated with the staff, some advocates preferred to deal with staff in person and wrote memos only to create agendas for meetings or to explain complex problems to senior staff. A few advocates routinely wrote memos regarding almost every action, and recorded every contact or conversation with, or about, a patient.

Outcome Data. The outcome data recorded by the PPAO underwent some alterations in the past year. In 1984/85 and 85/86, the following terms were used to measure outcome:

- complete satisfaction
- partial satisfaction
- not satisfied
- abandoned
- other

Apparently, these expressions held different meanings for different members of the program. PPAO Head Office, while acknowledging that in the first year of the program the term "complete satisfaction" may have been interpreted by advocates as meaning the client's level of satisfaction, noted that by 1984 there was a general understanding that "satisfaction" meant "instructions fulfilled." However, our data showed that advocates at five sites had always recorded their outcome data based on whether or not they believed the client was satisfied or not. These outcome measures were not necessarily derived from the client's feedback. As one advocate pointed out, if the patient didn't provide this information, then the advocate would decide how best to code the case.

In another example of the ambiguity of the outcome terminology, one advocate understood "partial satisfaction" to mean that s/he was satisfied but the client wasn't, while another advocate assumed that the expression meant that s/he fulfilled some of the patient's requests but not all of them.

Obviously, the outcome data were open to interpretation. Five advocates voiced a concern about the accuracy of data which were based on the subjective perceptions of the different advocates.

> *"The current coding needs fine tuning (eg. non-instructed cases don't fit). The stats are not accurate because we all have a different way of interpreting the data."*

> *"I think we all probably code differently. I know it's hard to make up codes to fit people's situations."*
>
> *(rights advisor)*

In 1986, the outcome data were revised to reflect more objective measures of the advocate's actions. Recognizing that the advocate frequently had no control over the final outcome of a client's case, and recognizing also that follow-up with every patient was not always possible, the PPAO developed codes that measured the extent to which an advocate was able to fulfill a patient's instructions. The codes that are now in use are listed below:

- instructions fulfilled
- instructions partially fulfilled
- instructions not fulfilled
- file closed pursuant to closing definition
- no instructions given/advocate would not act on instructions
- instructions abandoned by client

Since the meaning of the outcome measures is highly variable, we have made little use of this data in our study.

Self-Advocacy

The promotion of self-advocacy varied considerably. Although all advocates stated that they encouraged self-advocacy to varying degrees, patients reported it in only four sites. Advocates in three sites declared that self-advocacy was their primary strategy.

> *"I always give them (patients) the information, tools, and strategies to do it themselves. I give them questions and who to ask. If it doesn't work, I tell them to come back and I'll organize a three way meeting."*

> *"I encourage patients to advocate for themselves wherever possible. I believe staff will respond better to this."*

The following narration illustrates that some patients recognized that they were being encouraged by the advocate to solve their own problems.

> *"I wrote a letter to the administrator complaining of lock ups on the ward during any activities that take staff away- like church or yard. The administrator said there wasn't much they could do so I went to the advocate who told me*

> *that the Human Rights Commission was an option. I was given the address and a pamphlet, and I forwarded my own letter to the Human Rights Commission and the Ombudsman's Office. The case is still pending. I really pursued it on my own and the advocate encouraged that." (patient)*

The Use of Confrontation

In the previous section of this chapter, we noted that the advocacy process entailed the full spectrum of approaches, from informal negotiation with the staff directly involved, to seeking the intervention of a higher authority such as the hospital administrator. Whether the approach was one of negotiation or confrontation, depended upon a variety of factors that will be discussed below.

One of the objectives for the patient advocate, as outlined in the First Report of the PPAO, was to:

> assist patients with their complaints and provide an avenue for solutions by negotiation according to the patients' instructions.

The expression "solution by negotiation" suggested that a problem-solving or negotiating process should be the primary approach taken by advocates. This view was reiterated in the PPAO Policy Guidelines (Revised, Sept. 85):

> It is apparent that the degree to which the program would succeed depended upon the degree to which respect for and co-operation between the advocates and the hospitals could be achieved, on a voluntary basis (p. I).

When we discussed this statement with the advocates, most of them acknowledged that staff co-operation was important to them. They didn't enjoy deliberately antagonizing the staff and creating a hostile atmosphere.

> *"It is not easy to get their co-operation if you confront them; but if you can invite them to see a common client need, it usually works; you go in an inquisitive way... the Tom Sawyer approach; invite them to pick up the paint brush and illustrate what' s happening."*

However, six advocates stressed that even though staff co-operation was beneficial, creating goodwill in the hospital should not be the program's ultimate goal.

> *"I try to be social and yet I know you have to be careful about being co-opted."*
>
> *"Staff co-operation is not the bottom line. If they're doing something illegal, I can't be afraid of making waves."*
>
> *"You don't have to rely on goodwill... you should never tailor your advocacy around that focus. I would never give up going to the newspaper to keep goodwill..."*

In terms of the process that they preferred to use, eleven out of the twelve advocates indicated that confrontation was not their first choice, but rather a last resort. The twelfth advocate suggested that confrontation was not bad, depending on how you defined it. If it was defined as "upping the ante", then this advocate could see how people would view the regular tendency of going to administrative staff, Head Office or the Ministry of Health as confrontational.

The advocates indicated that although they were generally uncomfortable with confrontation, sometimes they were left with little choice, either because of the patient's instruction, or the staff's resistance to negotiating:

> *"I much prefer not to fight but I can't live with myself if there's a fight and I don't take it."*
>
> *"Confrontation is only used if people have been given a chance to fix things and it has gone on a long time without resolution."*

One advocate noted that advocacy will always be or appear somewhat confrontational in settings where the subculture is hierarchical and accepting of custodial care.

In identifying the factors that lead to confrontation, advocates talked about:

- staff attitudes towards patients - consistently ignoring patients' rights.
- staff attitudes towards the patient advocate - resisting attempts to negotiate or understand the advocate's or patients' requests.
- the advocate's process - if they choose to bypass staff and go to the top, they are perceived as being confrontational.
- the nature of the case - some cases such as treatment, non-instructed cases, and cases where the doctor lifts the

> certificate but doesn't tell the patient, tend to be more confrontational.

Advocates at five sites mentioned that some staff may have perceived the advocate's process to be a confrontational one, even though the advocates themselves may not have intended to be confrontational.

Advocate Style and the Advocacy Process

It became clear from the analysis of staff and advocate data, that the personal style of the advocate was an important factor, which had an influence on their advocacy process. Furthermore, the limited PPAO guidelines on the advocacy process, combined with the isolation of the advocate, allowed for a great deal of autonomy and variation in the approaches of advocates to their casework.

From our qualitative analysis, different styles of advocacy were identified, ranging from a low key, conciliatory, educational, and problem-solving approach to a more adversarial and confrontational approach. While all advocates used approaches from different parts of the continuum, depending upon the issue, the analysis of patient and staff responses suggested that some advocates tended to use approaches which clustered around one end of the spectrum. For example, more of the advocates with legal backgrounds tended to use relatively formal styles of negotiation and communication that they admitted might be perceived as confrontational by the staff. The language and actions of these advocates were clearly more adversarial.

> *"Supervisors are usually more available; I usually bypass front line staff."*
>
> *"I write memos to tell the staff what to do or to set an agenda for a complex issue. It makes clear documentation on each case. If staff then phone, I confirm the conversation in a memo. It's probably the strategy I've been most criticized for."*
>
> *"It is staff ignorance that makes things more confrontational. I try to get them to understand we are negotiating. They refuse to negotiate. Sometimes I make a threat and they perceive that to be confrontational. I only do this when I'm prepared to carry out the threat such as going to a higher authority."*

Advocates who tended to use approaches from the more educational end of the spectrum, stressed that they viewed their job as creating attitudinal changes that conditioned behaviours so that the need for enforcement concerns would be minimized. They recognized the importance of making frequent staff contacts, working with staff to solve a problem, and teaching staff to be advocates themselves, and promoting self-advocacy.

> *"My goal is to teach others to advocate -- patients and staff. I make nurses live up to the RNAO guidelines on advocacy. And I always try to give patients the information, tools and strategy to do it themselves, if they're at all able."*

> *"I have a problem-solving approach. I work with patients and staff. Often, I get the patient's side, then the nurse's side. I tell the nurse to talk to the patient. They say 'oh, what a good idea!' It's like a revelation to them."*

Regardless of their background, most advocates realized that the more confrontational approach could have serious, unintended consequences. Six advocates spoke of how confrontation impaired their relationship with staff. The communication barriers that were erected made it very difficult for future negotiations. Three advocates expressed their concern that confrontation can "backfire on patients", in the form of staff retaliation. This could narrow the chances for the successful resolution of the patients' complaints. Finally, one advocate spoke of the tremendous energy drain that resulted from the more confrontational approach.

Staff perceptions of these style differences will be discussed in the next section.

Summary

Several variations in the advocacy process were identified, including documentation and recording, promotion of self-advocacy, and the use of confrontation. Variations were partially attributed to differing styles of the advocates.

Some of these variations point to the need for guidelines and support which might assist advocates in such areas as promoting self-advocacy or how to escalate a case in a step-by-step fashion. Head Office's recent initiatives in this area should assist advocates in gaining a deeper insight into the advocacy process, thereby increasing their effectiveness as advocates.

D. PERCEPTIONS OF THE EFFECTIVENESS OF THE ADVOCACY PROCESS

Recognizing that "satisfaction" was an important indicator of the advocate's effectiveness, all respondents were asked to identify the sources of their satisfaction or dissatisfaction with the advocacy process. In the following section, we will link respondents' perceptions to the basic case work process outlined in Section B.

Very few people - patients, staff, or families - had a total picture of the case work process. In a particular case, for example, an individual staff member might only have been aware of the portion of the process that directly affected them. As a result, their comments were largely based on a limited perception of the case, combined with hearsay from others. Consequently, we found that, at times, there were contradictions in what various levels of staff had to say about the process.

As we evaluated the advocates' effectiveness, it was important to keep in mind that ultimately the role of the advocate was to follow his or her client's instructions. Therefore, it was the client who could provide the best measure of the advocate's effectiveness.

> *"Since the advocate is accountable primarily to the client, the criterion for successful advocacy is the degree of satisfaction to the client. To what extent was the client's grievance redressed to his or her satisfaction? (PPAO, 1987).*

Patient Contact/Initial Meeting

Patients complimented advocates on their listening skills and their respect for patients. This was often in contrast to hospital staff who were perceived by patients as not caring to hear about the patient's point of view.

> *"The advocate's rules are different, they act different; they want information from you. The doctor just talks and puts you in a room."*
>
> *"It's somebody normal to talk to."*
>
> *"I had lots of chances to get my feelings out."*
>
> *"They are a sounding board, someone to listen to you."*

> *"They always treated me with courtesy and respect."*

In the majority of sites, patients commented that the advocates were approachable, accessible, pleasant, compassionate and understanding.

> *"She is sincere, gentle, a kindred spirit; she is honest and straight forward. I love her."*

> *"He is polite and nice. He even came on a Saturday to see me."*

> *"For me, she makes it more comfortable... She talks to the staff. She picked my spirits up."*

Families were not very specific about their level of involvement in the advocacy process. However, their comments on the process were generally positive. They felt that the advocate took the time to explain things, to listen and empathize with the family, and to arrange inter-disciplinary meetings.

Information Gathering

Some staff complained, that while advocates had complete access to information, they were sometimes reluctant to share that information because of their strict code of confidentiality. Some administrators were particularly upset when they believed that the advocate's interpretation of confidentiality prevented the administrator from doing his/her job.

> *"I get no feel for the level of complaints and where they are. I know I have a problem with telephone access for patients. The advocate said there were many complaints about it. I asked which wards had the highest level of complaints. I have a limited budget and thought I'd begin to solve the problem where it was most serious. The advocate said I couldn't be told due to confidentiality. It's a shame; it could be a useful resource for me."*

While respecting the confidential nature of individual cases, several nursing administrators felt that if advocates could have been more forthcoming about ward issues it would have facilitated co-operation and solutions.

> *"We couldn't get information about the number of patients contacting the office. It would be helpful to have more reports on where requests are coming from - what wards, what type of patients."* *(nursing administration)*

> *"We should be able to talk to patients about their issues -- the big issues that a whole group is concerned about."*
>
> *(nurse)*

While aware of staff's concerns around the advocate's access to information, advocates were adamant about maintaining confidentiality. The impact of this procedure was appreciated by a few patients. An advocate notes the difference between patient and staff views.

> *"I don't betray confidence, unless a person is going to hurt someone. Some staff are outraged that I keep confidence; others are angry because I follow instructions. Yet in practice, maintaining confidence is one reason why patients have confidence in me."* *(advocate)*

Direct Action

Patients were impressed with the promptness of the advocate's response to their call and the speed with which the advocate worked.

> *"He was very quick in getting back to me."*

> *"If I need him in a hurry I'll call his office and he'll say 'come on over right now."*

> *"I got it done the same day; I didn't have to wait."*

The major sources of satisfaction for families were the advocate's availability, their ability to act as an intermediary between staff and families, and the fact that they encouraged families to turn to them with their concerns.

> *"I would have felt lost without her... a very real plus."*

> *"It's very good to have a go-between - between you and the hospital."*

> *"Just to know that they offer the service, is good."*

Clinical staff were satisfied with the advocacy process when the advocate helped them with problems. Case examples cited reflected three themes:

The advocate's intervention reduced troublesome patient behaviours.

> *"Two patients were always fighting and the advocate sat down with them and drew up a contract."*
>
> *(nurse)*
>
> *"A patient's husband was being abusive and threatening on the ward. Right away we sent him to the advocate. She took the pressure off us."*
>
> *(nurse)*
>
> *"We had a patient who was continually phoning lawyers (40 lawyers in eight days) and making threatening calls to his sister-in-law. The advocate was able to stop both these behaviours."*
>
> *(nurse)*
>
> *"The psychiatrist initiated the transfer of a mentally retarded patient. The advocate was invited to assist. She had information and knew who to contact."*
>
> *(psychiatrist)*

The advocate intervention dealt with matters outside the hospital.

> *"An incompetent patient wanted to change his will. The advocate contacted a lawyer. She prepared the patient to see the lawyer and she educated the senior clinical staff about changes to wills and the rights of patients to control these matters."* *(nurse)*
>
> *"A patient lost his belongings walking in a cemetery. The advocate worked with the staff to resolve this situation."*
>
> *(nurse)*

The advocate supported staff efforts or assisted in achieving some benefit sought by staff for patients.

> *"We've been trying to get a handi-bus for our patients for two years. The advocate was the catalyst who finally did it. She gave the whole issue a rights perspective and it was finally approved."* *(nurse)*
>
> *"We've been talking for ages about unlocking the doors on our ward. It just seemed to go on and on for years and never be resolved. The advocate made an issue out of it and now we have an open ward."* *(nurse)*

There were two main sources of dissatisfaction for the staff about the effectiveness of the advocates' process. First, staff did not approve of a confrontational, threatening adversarial approach. They want to know that the advocate will follow a predictable process which will escalate to a confrontational mode only in extreme cases. The second source of dissatisfaction was based on staff's perception that the advocate interfered with treatment decisions.

> *"We were rationing cigarettes as part of the treatment plan. He told the patient that she has the right to spend money as she chooses. This patient got violent when she ran out of cigarettes and the staff had already arranged to have the patient's cigarettes supplemented. We were very frustrated that the advocate said she could have unrestricted cigarettes, especially when we'd gone to the trouble of trying to help the patient ourselves. At times like that you feel like giving up."* *(nurse).*

Administrators were satisfied with the advocacy process when:

- advocates worked through the organizational channels.
- they assisted the administrator in identifying problems he/she could address.
- they brought expertise to certain policy committees of the hospital.
- they had a good, cooperative working relationship with staff.

> *"I insist that the advocate work from the bottom up. I only want to be involved when it is essential."*

> *"I have called on the advocate to help me with a legal case and with a hospital policy. These are issues concerning abuse and he's a real expert on these things."*

> *"She's pro-active, therapeutic and positive. She knows how to deal with staff in a positive way, yet she can be really tough when it is necessary."*

In all interviews with staff, they were asked to provide a single phrase to describe the process of the advocate. In our analysis, the descriptions fell into two categories which are summarized in the following table.

Table 7

Staff Descriptors of the Advocate's Process

Educational/Conciliatory	**Adversarial/Confrontational**
• negotiator/mediator	• adversarial
• goal oriented /problem-solving approach	• confronting,threatening, demanding, aggressive interfering
• escalates cases from lowest level	• guilty until proven innocent
• caring and polite	• legalistic
• considers consequences for patient	• anti-hospital and anti-medicine
• good rapport with patients & staff	• sees patient in isolation

---

The sites where staff used negative descriptors most often, were the sites described earlier where advocates tended to be more adversarial. However, patient satisfaction/dissatisfaction with the process did not vary among sites. Nevertheless, these staff perceptions are so congruent that they suggest some very important feedback to the PPAO. Advocates who are perceived as adversarial are viewed in *very* negative terms by staff. Since advocates themselves suggested that confrontation impaired their relationship with staff, these data raise the question as to whether more adversarial advocacy actually impairs the advocates ability to resolve the clients problem in an effective manner with staff.

Follow-up

Most patients felt quite involved in the advocacy process and most believed they were kept informed about their case. Bradley and Murphy (1980) have found that patients who were most involved in the advocacy process, were most satisfied, regardless of the outcome of their case. In general, our data supported this finding.

> *"I was the main issue; I felt very involved."*
>
> *"She involved me as much as I was willing to be involved. She'd ask me to make calls and give me phone numbers but if I wasn't comfortable, she'd help me make the calls."*

A minority of patients commented that they had little involvement or feedback from the advocate.

> *"He didn't let me know what was happening."*

> *"I don't know if he followed it up -- he never got back to me."*

> *"I don't know if the advocate spoke with the nurses,that I cannot say. But I got my money. I think she might have written a letter to the ward."*

Most patients understood that the advocate was "on their side" or at least independent of hospital staff.

> *"The staff are on the doctors' side. The advocate is not on anybody's side."*

> *"The advocate is on my side... It makes me feel good - someone who cares."*

> *"If I'm having a problem they (advocates) can tell me what the rules are. They can give me another opinion -- a sane opinion."*

Family members also stated that they had good feedback and involvement in the advocacy program, and that the advocate seemed to support parent advocacy. Two families thought that they did not have enough communication or involvement in the advocacy process.

> *"The advocate didn't do that much; I was disappointed with the advocate. They listen to the doctor, not to you or the patient."*

End of Case

The majority of patients stated that the advocate did his/her best even if the outcome of the case was unsuccessful. They felt better just knowing that the advocate was there.

> *"She did the best she could and she is still looking into it. I am very pleased with it."*

> *"I am more than satisfied with the advocate. They've done about as much as they could. They went as far as they could and they always treated me with courtesy and respect."*

> *"I have always found the patient advocate office people to be very helpful, encouraging to the patient, and have known them to treat each and every patient as a human being whereas the same cannot be said of some of the doctors and nurses... We definitely need the advocate here."*

The main source of dissatisfaction for a small minority of patients was the perceived lack of power of the advocate. Nearly all of these complaints came from Oakridge patients and from a few forensic patients in other hospitals. The primary complaint was that the advocates had no power to deal with abuses in the system.

> *"They've got no power whatsoever to get you out of here. It's the psychiatrist that has the power."*

> *"The advocates don't have the authority at times to do more than they can. Their hands are bound."*

> *"The advocate's office should have some power. If something is done wrong, after investigating, they should have the power to make things right."*

The advocate's perceived lack of power was also a major source of dissatisfaction for families. This was mentioned in four sites.

> *"The doctors have most of the control. The advocate's hands are tied. They couldn't force them (M.D.s) to do anything."*

> *"The advocate has no legal clout; can just recommend things."*

> *"She did all she could; she doesn't have the power to do much more."*

Although families were generally satisfied with the process, a few families were not happy because:

- the patient was released
- the patient was not released.
- there was no change.

Outcome Data. Advocates at eight sites complained that the current outcome data were an inadequate measure of their effectiveness. According to the advocates, "instructions fulfilled" may reflect their basic actions, but the term doesn't begin to capture the process, the time spent on educating or providing information for self-advocacy, or the final outcome for the client.

> *"The outcome data shows how much traffic the advocate handles, how many instructions, how you fulfilled them and how much the advocate wants to have. But it is useless in evaluating the effectiveness of the advocate. We don't need feedback about what instructions I've fulfilled. My effectiveness depends on what the clients think; I get some of this informally. I would find it useful to have something that would measure client feedback and satisfaction instead of instructions fulfilled."*

> *"I can fulfill every instruction, but not guarantee the outcome; we should always be fulfilling every instruction; instead we should code "advocate not able to act on instructions"; now we could have 100% instructions fulfilled, but have 100% non-accomplishment; the paperwork should tell us what we're winning and what we're losing; where we are not getting results e.g. so do I need to educate social workers more."*

> *"I'd love more realistic feedback... the terms don't talk about how effective I've been. How can anyone evaluate me? How do they really know?"*

The need for more feedback to clients was discussed by seven advocates. Because advocates believe that they are ultimately accountable to their clients, they also feel that patients should have some formal or informal means of evaluating the advocate.

> *"I really wish the clients had more input in assessing us... I think there has been far too much attention paid to the opinions of staff and the administration. I'm not there to serve staff."*

Advocates' suggestions for the changes that they would like to see in the collection of data, are discussed in greater detail in chapter VII on Internal Organization and Resources.

Suggestions for Improving the Advocacy Process

Respondents had a number of suggestions for improving the advocacy process. Although a minority view in each case, some patients felt the advocacy process could be more effective if:

- advocates gave more regular and detailed feedback to the patient.

- the advocate had more power to implement change.

Staff suggested that the following changes would improve the advocacy process:

- a consistent educational/problem solving approach to advocacy, rather than the uncertain adversarial style.
- improved communications with staff.
- an emphasis on "informed" rights for patients.
- more attention to issues that staff perceive as significant issues, rather than issues perceived by staff as petty, such as access to money, a telephone, or cigarettes.
- common courtesy, rather than rudeness and disrespect which some staff say they had experienced.

Skills Needed By An Advocate

We found broad agreement among advocates and other respondents about the skills an advocate should have.

- excellent interpersonal skills: the ability to relate, mediate, negotiate, communicate, be diplomatic and genuine.
- broad life experiences and a good network of contacts.
- independence with a strong sense of self.
- firmness and persistence.
- experience with the local community in which the advocate is working.
- mental health knowledge.

There were other skills on which there was not consensus; for example, a minority of respondents felt that legal training might also be important. Given the nature of being an advocate in an institutional setting, it probably makes sense that there be some balance between mental health training and legal or human rights training. In addition to skills, advocates obviously need a variety of strategies to be effective with the advocacy process. In assessing our interview and observation data carefully, it seemed that *good judgment* was the key factor which underlies many of the strategies. For example, effective advocates carefully judge when and how to support self-advocacy, as well as when and how to escalate a case to higher authorities. Advocates who are more educational or problem-solving oriented, for example, would need to make these kinds of judgments on a regular basis. According to the PPAO's own goal of resolving patients' problems primarily via "negotiation", our data have suggested that some advocates use better judgment in their choice of strategies and are thus more effective in meeting this program goal.

Summary

While advocates' allegiance and accountability are primarily to their clients, advocates operate in a setting with many other actors who have varied agendas. Respondents' perceptions of the effectiveness of the advocacy process have illustrated that patients, floor staff, and administrators have differing views on what constitutes effective advocacy. These varied agendas clearly cause tension when the advocacy process deviates what people's expectations. Our data show that this tension is much greater at those sites where advocates are perceived by staff as being adversarial.

While Milner (1986) has noted that conflict is inherent to the advocacy process, it does appear that the style and approach of some advocates may be more adversarial than needs to be the case. In a comprehensive review of advocacy programs in the United States, Bradley et al. (1982) commented:

> "it is interesting to note that negotiation not litigation was the strategy of choice among the projects. The use of negotiation also resulted in the most favorable outcomes. This finding to some extent dispels the notion that advocacy projects employ confrontational means to represent their clients to the exclusion of other techniques. In fact, virtually every project leans heavily on negotiation as a means of resolving disputes."

It is important to emphasize that a focus on negotiation and education does not preclude the use of confrontation and other adversarial strategies. Advocate and patient data point to the fact that there are "difficult problems to resolve" on behalf of patients to which the system may not easily respond. It appears that the advocates' judgment in deciding when and how to utilize these strategies is an important measure of their effectiveness.

Finally, our effectiveness data help us reflect upon the ultimate goal of institutional advocacy. While we concur with the PPAO and the advocates that an advocate's primary allegiance is to clients, we note that the advocacy process often lends itself to a complementary goal:

to create systemic changes that are rights-consistent, and that bring treatment in line with rights. The more educational, problem-solving advocates work more consistently toward this broader, longer term goal.

RECOMMENDATIONS

1. The PPAO should develop strategies for reaching out to educate non-client patients about the PPAO. These strategies need to include concepts such as patient meetings and patient government.

2. Ongoing systematic education of staff about rights and the mandate of the Advocate Office needs to be developed. This education should be designed to create a more positive image of the Advocate Office and to provide a needed balance to the more adversarial image of its advocacy work. Special consideration needs to be given to how this education can influence those psychiatrists who are negative about the program.

3. A problem-solving/educational approach to the advocacy process needs to be re-affirmed as the primary approach for PPAO advocates. This approach should be reinforced through: an orientation program, ongoing professional development programs, and annual performance reviews. It must also be recognized, however, that certain circumstances require other advocacy approaches.

4. The PPAO Head Office needs to expand its pilot work in developing training sessions to enhance advocates' effectiveness with the advocacy process. The training should be in such areas as negotiating, how to promote self-advocacy, ways to escalate a case, and other needed advocacy strategies.

Chapter IV

EFFECTIVENESS:

NON-INSTRUCTED AND SYSTEMIC ADVOCACY

Most of the advocacy initiatives of advocates are based on client instructions. There are two other types of advocacy which are within the mandate of the PPAO but which are not dependent on the instructions of the client. Systemic advocacy refers to advocacy which addresses issues that affect a broad segment of the patient population. Systemic advocacy is mainly concerned with policy and procedural change at the hospital or Ministry level and can be initiated by Head Office or an individual advocate.

Non-instructed advocacy refers to cases where the advocate is working on behalf of an individual who has been unable, for one reason or another, to give instructions to the advocate about the exact problem or how to proceed.

Non-instructed cases are generally a form of individual advocacy, but they relate in an interesting way to systemic issues in that both expose larger institutional concerns. These types of advocacy are often pursued without instructions. For that reason, we look at both systemic and non-instructed advocacy in this Chapter.

A. NON-INSTRUCTED ADVOCACY

According to policy guidelines developed by the PPAO, non-instructed advocacy forms a small but important part of the work of advocates. The guidelines indicated that three per cent of all advocacy being conducted was non-instructed. The assumption behind these guidelines is that there are some individuals in psychiatric hospitals who are more vulnerable and less able to speak for themselves. It is further assumed that advocates will "be on the lookout" for situations which require the advocate's intervention and support.

The process of non-instructed advocacy is neither well defined nor well understood. While there is some discussion in the literature about the value of advocacy for more vulnerable people (Wolfensberger and Zauha, 1973), this seems to be a relatively new area for people working in mental health.

Degree of Emphasis on Non-Instructed Advocacy

Our data indicated that non-instructed advocacy received very little emphasis at most hospitals and within Head Office. This conclusion is drawn from several inter-related sources of information;

- Slightly less than 2 per cent of advocate's cases were non-instructed.
- Advocates were not required to submit statistics on non-instructed cases as they do for all other case work.
- The first two annual reports of the PPAO made no mention of non-instructed cases.
- Seven advocates indicated that they spent very little time or emphasis on non-instructed cases.
- Staff in the PPAO office emphasized that non-instructed advocacy is an area that needs "substantial improvement".
- Ministry of Health officials expressed concern that non-instructed cases "seemed to be ignored in a number of hospitals."

Reasons Cited for Little Emphasis on Non-Instructed Cases

There were four major reasons cited by advocates, the PPAO office, and Ministry of Health officials, which explained or rationalized why there was little emphasis placed on non-instructed issues:

- they tend to be more annoying to staff and more confrontational.
- they take more time than instructed cases.
- advocates are often uncertain about how to proceed with cases from psychogeriatric and mental retardation wards.
- advocates are ambivalent or hesitant about not taking instructions.

The main reason cited for little emphasis on non-instructed cases was that they tended to be more annoying to staff and more confrontational. Advocates at six hospitals mentioned non-instructed cases tended to make the staff uncomfortable and less co-operative. One advocate outlined the difficulty:

> *"Non-instructed cases are difficult because people don't readily give information and medical staff get upset if they think you are not taking instructions."*

Another advocate noted that on wards which have a lot of vulnerable people who have difficulty speaking for themselves staff tended to be very suspicious of the advocate.

> *"This ward is paranoid about me. I just go in to look around or to select some files...I have told them that if there was a problem I would tell them and if not, don't worry, but they obviously do worry a lot."*

While one advocate described the non-instructed advocacy process as "walking on eggs," only two advocates indicated that they don't do any of these cases.

As a second reason for the limited emphasis on non-instructed cases, several advocates and the PPAO office both indicated that non-instructed cases take more time than instructed cases. This makes sense given the nature of the non-instructed process. If an individual client cannot instruct the advocate, then it obviously takes time to build a relationship or find a substitute decision-maker. Only a small minority of advocates indicated they were willing to spend this kind of time, but it seemed to depend upon whether or not the non-instructed case might have the potential to be linked with some systemic advocacy. We shall discuss this in a subsequent section.

Third, advocates and officials from the Ministry of Health indicated that advocates' uncertainty about how to proceed with cases from psychogeriatric and mental retardation wards significantly limited the amount of non-instructed advocacy. One advocate's comment typified this concern:

> *"I suppose my lawyer training influences me because I don't feel very effective here (with non-instructed cases). I just don't know what to do with the geriatric ward."*

A Ministry of Health official emphasized that we all avoid elderly people and advocates are probably no different. Similarly, this person noted that many of the people who cannot give instructions to the advocate are on mental retardation wards.

> *"This has been an issue ignored by advocate associations for the mentally retarded and advocates simply don't know where to start."*

Fourth, some advocates indicated ambivalence or hesitation about not taking instructions. It is interesting to note that advocates who were trained as lawyers emphasized hesitation. Nevertheless, it is a very real dilemma related to the fact that "instructed advocacy is easier to conduct." One advocate framed her comments in terms of the evolution of the patient advocate program:

> *"At first the program was under pressure to establish themselves and it was easier to be able to say 'you were following instructions of another person'. Part of our hesitation relates to this history."*

Our data from families as well as advocates' perceptions of the role of family seemed to reiterate this hesitation about not taking instructions. Several advocates indicated that they would not take instructions from families, but if alerted to something by a family member, they would use that information to go to the patient to see if he or she wanted the advocate to do something on their behalf. While this seemed like a reasonable process, the data suggested that people who are more vulnerable and unable to speak for themselves are less likely to receive support from the advocate than people who can articulate instructions.

The dilemma of whether or not to proceed with a non-instructed situation was not easily resolved. One advocate highlighted the difficulty expressed by several advocates with not taking instructions:

> *"The danger here is that I don't want to interfere with the person's self (personhood). I do everything to determine that the person would want this done."*

The concern for some advocates was how to "avoid being paternalistic" while still ensuring that the patient's rights and needs were being respected. Three advocates noted that this dilemma applied equally to the substitute decision-maker.

Sources for Non-instructed Cases

Advocates identified five sources for non-instructed cases:

- Review of daily ward reports
- Family and friends
- Staff
- Observation while walking through wards
- Other patients

The most common source for advocates was the review of daily ward reports which advocates received daily from the hospital administration. All advocates indicated that this was an important source of information. Daily ward reports were compiled every 24 hours and gave a sense of the patterns and problems during that period. For example, new admissions would be listed, as well as situations such as the number of people in restraints, people who have signed themselves out, or any instances of tension between staff and patients.

Advocates were clear about the value of the daily ward reports.

> *"When something appears in the daily report, I check it out first with the patient, the staff, and the files. I generally only move at that point if the patient instructs me unless I am convinced that other action is necessary."*

Advocates also mentioned families and friends (6 sites) and staff (6 sites) as other very important sources for non-instructed cases. Surprisingly, only three advocates noted that walking through the wards and observing was an important source of information for non-instructed cases. These advocates noted that their observations were important because "so many institutionalized patients are accepting and passive" and "you need to get an ongoing sense of what is occurring on the wards." The role of staff as a source of information for both instructed and non-instructed cases is quite interesting. According to PPAO data, approximately 14 per cent of all referrals to the advocate offices were from staff in the hospitals. Advocates pointed out that many of these cases started as non-instructed but became client instructed once the advocate intervened and invited the patient to participate. In contrast, only 2 per cent of cases were referred from family and 1 per cent from other patients.

Effectiveness of Non-Instructed Cases

It is difficult to assess how effective advocates were in identifying, pursuing, and completing non-instructed cases. Nevertheless, there were several indicators from the information we gathered which raised questions about the advocates' effectiveness with non-instructed cases. Each of these indicators will be reviewed briefly here.

First, several advocates indicated that they felt they were not as effective with non-instructed cases. As discussed earlier, advocates believed that non-instructed cases were more difficult, took more time, and required a sensitivity and patience which may conflict with other demands of the job.

Second, data from advocate interviews and an analysis of several non-instructed cases indicated that the process used by advocates varied widely, was generally unsystematic, and lacked coherence with any standards or guidelines. As discussed in Chapter III, the first step in instructed advocacy involved the patient sharing his concerns with the advocate. The process with non-instructed advocacy was different. The first step involved the advocate observing or being told about an incident or an issue of concern. At that point, there were a series of decisions which the advocate had to make regarding how to pursue the case. Most advocates initially did background research and contacted the person to get as much instruction as they could. One advocate was particularly sensitive to this latter point:

> *"Some people can't instruct, but they can absorb what you are trying to do, and you need to keep people informed."*

Case analysis indicated that advocates differed widely in how they proceeded if a patient was either unwilling or unable to give instruction. One advocate was told by staff that a pregnant woman was heavily medicated as a restraint measure. When the advocate tried to talk to this woman, she told the advocate to "go to hell." The patient advocate discussed with the staff whether they had ordered an obstetrical consultation for the woman. The staff pursued this, ordered the consultation and medication was eventually decreased.

A small minority of advocates, however, would consider this kind of intervention to be inappropriate because the patient had obviously not instructed the advocate. As an illustration from another case analysis, one advocate was approached by a social worker and asked to investigate a patient with a black eye. After the advocate was unable to gain instruction from the patient, the advocate wrote to the Director of Nursing and asked that charting be improved. The advocate also wrote back to the social worker and said advocates could not act without instructions from the client.

The current PPAO guidelines on non-instructed cases do little to assist the advocate in deciding which cases to pursue and how to pursue them. The guidelines do suggest that advocates visit any patient who appears to have had rights restricted, denied, or neglected. It also discusses the best ways to prepare an outline for how to proceed. Some advocates have used Head Office in a collaborative way to make decisions about non-instructed cases, but half the advocates were critical of Head Office for not doing a better job in the area of non-instructed advocacy.

> *"The PPAO has not done the research analysis to pick up larger issues and understandings that could help patients who cannot speak for themselves."*

At the same time, the new provincial coordinator indicated she wants to see non-instructed advocacy expanded and has begun to research this possibility.

Our data have suggested that advocates were having a very difficult time making some of the sensitive decisions which are required with non-instructed cases. Ascertaining that a person is unable to instruct may itself be a major decision, in addition to the fact that one then has to decide whether the situation requires advocacy or not. There is no doubt that part of the issue here is having the time to develop a relationship with people who are more vulnerable. One advocate's comment that "the squeaky wheel gets the grease" reflected the concern of a number of advocates that they simply don't have time to spend getting to know people who are not seeking out the advocate's help.

A related "ethical" problem concerned access to records in non-instructed cases. Staff at Head Office noted it was a concern for advocates to access client records when the person her/himself cannot authorize such access notwithstanding the advocates ability to obtain access as a result of the S.5 designation.

When assessing the process of non-instructed advocacy, a final key issue was when and how to use *substitute decision-makers*. While only one advocate indicated "struggling" with this issue, there was no question that if the family or a friend of the vulnerable person was advocating or speaking on his or her behalf, then there would be less conflict directed at the advocate. In fact, our family data showed that families themselves have been quite successful at advocating on behalf of family members in institutions. Again, in developing clear guidelines for non-instructed advocacy, questions around substitute decision-making would have to be carefully considered. The PPAO should get some assistance from the Guardianship Legislation which is soon to be introduced in Ontario and is expected to propose guidelines for substitute decision-making.

Link to Systemic Advocacy

Advocates at six hospitals viewed non-instructed cases as a very important source for systemic advocacy. Furthermore, the advocates' submission to this evaluation highlighted this point:

> *"Most of our advocacy is client-initiated and instructed, which preserves the principle of self-determination. While non-instructed advocacy seems paradoxical to self-determination, in that it is not client centred, this enables institutional and systemic change and benefits all patients."*

One advocate's perception that "advocates tend to tackle most non-instructed cases as systemic" could be partially explained by advocates' discomfort with trying to pursue individual advocacy without instructions. It may also be explained by the fact that some of the non-instructed issues were fundamental rights issues which challenged some of the custodial and programmatic practices of the institution. The systemic approach lessens the need to address an individual issue over and over again. One advocate's comment reflects this widespread view.

> *"Non-instructed advocacy is very important for systemic change. People on geriatric wards in many ways require the most advocacy, but they are broad issues such as use of restraints, the need for properly fitting clothes, the need for fresh air, problems with toileting and other issues which are experienced by a wide number of people."*

It is difficult to judge how effective advocates have been in terms of translating non-instructed cases into systemic advocacy. One reason is that the PPAO office has not required advocates to record data on non-instructed cases. While the research team was able to gather some information on specific cases, the thoroughness of the recording was very limited. Nevertheless, at least four advocates have been very careful about recording and translating non-instructed cases into systemic advocacy. As noted earlier, some advocates made no attempt to work on non-instructed cases, while others seemed more hesitant in terms of how to proceed. Typical of this latter group was one advocate who noted that non-instructed cases could be an important base for broadening systemic advocacy, but up to this point he "wasn't sure how to proceed with this kind of work."

Translating non-instructed advocacy into systematic cases may be an important starting point for advocates working on wards with more vulnerable patients.

Implications for Mental Retardation and Psychogeriatric Wards

Patients in psychiatric hospitals who are most likely to be unable to speak for themselves will generally be found in mental retardation or psychogeriatric wards. Several advocates, administrators, and Ministry of Health officials indicated that advocates should expand and improve their activities with the psychogeriatric and mental retardation wards. It is interesting to note that 6 per cent of PPAO clients were over the age of 65 but that hospital patients this age constituted approximately 23 per cent of the total hospital population. The PPAO has responded to people whose primary diagnosis or label was "developmental handicap" in only 3 per cent of their cases.

Several advocates stated that it is "time" to emphasize non-instructed and systemic advocacy with people on psychogeriatric and mental retardation wards.

> *"Now that the program is established, four years of effective case work has identified where effective systemic work should be done. We need to work with geriatrics and mentally handicapped people, not just the Ministry and hospitals."*

Similarly, administrators at five hospitals noted that advocates did not effectively meet the needs of vulnerable patients, and that advocates should expand their activities with more vulnerable patients. Only one hospital administrator said that the advocates should not spend more time with vulnerable patients because "they have their families and the public trustee." Five administrators felt the exact opposite and noted that non-instructed cases were being ignored by advocates:

> *"Advocates tend to respond to the verbal people. We have lots of mentally retarded people here. The PPAO office is almost totally reactive, so that people who are labelled mentally retarded or psychogeriatric get by-passed."*

The administrators who wanted advocates to expand their activities on these wards had cautions and suggestions about how this might work.

> *"We need a more independent view of the mentally retarded and psychogeriatric wards. However, it might have to be a different mandate...several issues need to be resolved in dealing more effectively with non-instructed cases on these wards, including substitute decision-making."*

> *"Taking instruction is a very legalistic thing... the whole idea makes it hard for advocates to work with vulnerable patients. It is an abdication of human responsibility to do nothing with these people and taking instruction is a very convenient loophole for them."*

This last administrator suggested that the advocate program be revamped to be more similar in style to that of an ombudsman's office, which would be designed to make suggestions to administration for improvements, "not just focus so much on the legal."

Our data suggest there are other implications for non-instructed advocacy with these wards.

- Several people we interviewed noted that these particular populations tend to be extremely vulnerable. This challenges advocates to understand the nature of people's vulnerability and to learn more about aging and mental retardation. One advocate has already, on her own initiative, attended workshops related to elderly people. Two advocates seemed to have a commitment to, and understanding of, non-instructed advocacy on these wards and could be an important resource for other advocates. Additional resources may also be needed to support the PPAO in expanding non-instructed advocacy.

- There are people on these wards who would be able to instruct the advocate and it is important that advocates *not* assume that everyone is incapable of giving instructions. A more fruitful avenue would suggest advocates should increase their monitoring, observations, and activity of getting to know patients. As this process occurs, some patients will begin to instruct the advocate about concerns they have. Other potential systemic cases will be identified by advocates and selected individual non-instructed cases could be initiated.

- It is clear from our field notes and interviews that many people on these wards are lonely and isolated from any family or social networks. Some people with developmental handicaps have family who visit regularly, but most have no visitors and very few relationships or social interactions. As a submission from Concerned Friends of Ontario Citizens in Care Facilities emphasized, there is a critical role for volunteers to become friends and develop relationships with lonely and isolated people in institutions. The use of volunteers to date has been extremely underdeveloped in this advocacy program. We are not proposing that advocates recruit volunteers, but rather that they generate interest in volunteers through community organizations who could expand relationships and informal advocacy on these wards.

- Submissions to this study have pointed to the fact that there are major voluntary and consumer advocacy associations which are deeply concerned about older people and developmental handicapped persons in these hospital settings. The PPAO Head Office could link with these groups in order to identify resources which might assist the non-instructed advocacy on these wards. Several advocates have indicated that they would need new strategies and new resources to do more effective instructed and non-instructed advocacy on these wards.

The suggested linking process might assist them in doing this.

Protecting Rights of Vulnerable Patients--Staff Perceptions

Staff generally expressed the view that they have had a major role in protecting the rights of people who cannot speak for themselves.

There was unanimous agreement amongst nursing staff that safeguarding the rights of vulnerable people was a primary role for nurses. Somewhat surprisingly, because this was a study on patient advocacy, advocates were never mentioned by nurses as having a role to play. Nurses strongly emphasized their role as advocates with people who could not speak for themselves.

> *"We have good staff and our staff know how to take care of patients."*
>
> *"Nurses will advocate on people's behalf - they always have. This is part of our understanding of the nurse's role. Advocacy is based upon knowledge of the patient."*

This notion of advocacy being part of the nurse's role was reiterated at most hospitals. The Directors of Nursing at five hospitals, however, seemed to put the role of advocacy for nurses in a broader context. One Director of Nursing, while noting that some nurses do act as advocates for their patients in certain instances, felt that advocates should work on more global issues that would improve the lives of patients who cannot speak for themselves. For nurses, the notion of protecting the rights of vulnerable people was clearly linked to "caring." The general perceptions seemed to be that if they cared enough and in the right kinds of ways, there would be no difficulties. Comments from two nurses reflect this perspective.

> *"I really think that the staff here care a lot and are the patient's rights workers. They have the best interests of the patient at heart."*
>
> *"We often have a staff person on each ward who cares a lot about these people."*

Staff at five hospitals mentioned that family members and relatives were important in protecting the rights of people who cannot speak for themselves.

> *"A lot of relatives work with our staff; they act as a liaison with the staff and patient."*

> *"On our psychogeriatric ward we have good relations and regular meetings with family and staff."*

None of the floor nurses or ward supervisors mentioned the role of advocates in protecting the rights of people who cannot speak for themselves. This is a particularly interesting finding, given the fact that in 1985-86, 6 per cent of the total referrals to the PPAO office came from nurses.

Physicians mentioned a variety of ways in which rights could be safeguarded for vulnerable patients, again noting the primary role of staff and physicians:

> *"We are the advocates - staff have traditionally been patient advocates, that is the best way to safeguard rights."*

A minority of physicians and psychiatrists emphasized that there should be a mandatory review process for informal, vulnerable patients. As one psychiatrist noted "there is a tendency for staff to be paternalistic, and there is currently no review process for informal patients and people tend to get lost."

Physicians mentioned the role of the advocate in protecting the rights of vulnerable people only at one site; a role for family and relatives was also mentioned at another site.

Some of the data from physicians seemed to contradict our impact data (Chapter V) which indicated that psychiatrists and physicians do not see an overlap between their role and that of the patient advocate. Perhaps, then, in terms of more vulnerable patients, when psychiatrists talk about staff as advocates, they were really referring to other members of the medical staff who work more directly with patients.

Social workers also noted the role of staff in safeguarding the rights of vulnerable patients. In particular, many social workers felt that they have traditionally had an important role in safeguarding these rights. The role of the advocate was mentioned at several hospitals, even though at some sites social workers noted that perhaps their role overlapped with the advocate's in this area. Our data suggested that social workers have a wide variety of opinions on this issue and no consensus seemed to be occurring. Some social workers, for example, expressed frustration that advocates have not been able to do more on the psychogeriatric and mental retardation wards.

> *"There was abuse taking place on the mental retardation ward and that was widely known, but our advocate couldn't go on the ward because she wasn't instructed by a patient."*

Other social workers felt that they "ensure rights" and "encourage family members to be supportive" and that these advocacy functions were well maintained through their participation with vulnerable patients.

Summary

The data on non-instructed advocacy shows that this type of advocacy has received little emphasis at most hospitals and at the PPAO Head Office. Interviews and case analysis identified a number of indicators which suggested that non-instructed advocacy was not being conducted in as effective a manner as instructed advocacy. Our findings also have broad implications for mental retardation and psychogeriatric wards, and we have identified some resources which would assist advocates in these areas.

The concept of advocacy for more vulnerable patients has also raised other important, complex advocacy questions. For example, several advocates were very concerned about "not taking instructions," or "being paternalistic" if they initiated a lot of non-instructed advocacy. We concur that this is a vital ethical issue related to how advocates decide what someone's needs and interests really are. Milner (1986) has proposed that we need to conduct indepth ethnographic studies, including recording advocate/patient interactions, in order to better operationalize what advocates do. The methodology for this study, of course, has not allowed us to detail such decision-making processes.

Staff's perceptions that they serve as the primary advocates for more vulnerable patients raised another crucial advocacy issue. In the last decade, professional groups such as the Registered Nurses Association of Ontario, have increasingly identified "advocacy" as an important goal for staff. In some ways and under certain circumstances, there is no doubt that professionals can perform an advocacy role. In other ways, however, staff perceptions may illustrate how the word "advocacy" has become obscured because it means so many different things to different people.

In a comprehensive paper on the meaning of advocacy, political scientist Milner (1986) argued that professionals have increasingly defined themselves as advocates as a way to minimize the conflict inherent in the advocacy process. As an expression of this professional view, psychiatrists Kapolow and Bloom (1977) have noted that the "present day connotation of conflict or antagonism is not inherent in the basic concept of advocacy, but rather results from the manner in which some advocates pursue their work" (p. vii).

Another way to interpret these data, is to recognize that by "taking on" the role of advocate, service professionals may be trying to reduce the need and demand for outside advocacy.

The PPAO submission to the O'Sullivan Review of Advocacy (1987) further suggested that advocacy must redress the power imbalance, and involves speaking out on behalf of the powerless or vulnerable against the powerful. Advocacy also includes the conscious and deliberate goal of influencing a "target to bring about change" (PPAO, 1987).

In conclusion, there is little doubt that staff have a vital role to play in supporting and safeguarding the rights of more vulnerable patients. Further analysis, however, has suggested that the role of staff as advocates is limited both by their institutional positions and by a more precise definition of advocacy.

B. SYSTEMIC CASES

Systemic advocacy is an advocacy process addressing rights and issues that affect patients in general as opposed to a single patient. Local systemic advocacy refers to concerns arising on a ward, in one hospital or in one community. Provincial systemic advocacy refers to issues that become province-wide concerns and involve Head Office activity.

In this chapter, we describe systemic advocacy as practised by the PPAO. A combination of file information and interview data has been used to develop our findings in this area. We should note, however, that our research was limited by the fact that systemic files were often incomplete and important details were frequently missing.

The Basic Systemic Advocacy Process

The basic process of systemic advocacy is illustrated in Table 8. The chart portrays the complexity of systemic issues, including the wide variety of creative strategies used to promote systemic change. Some features of the chart are discussed in the following section.

Sources of Systemic Cases. Systemic issues were usually initiated by the advocates based upon a succession of similar individual cases. Two advocates best expressed this approach:

> *"You get tired of doing individual cases over and over and decide to tackle the damn thing".*

> *"You have six patients saying the same thing from different wards".*

Other sources of systemic cases included:

- one individual case, when explored, indicated a larger issue
- one glaring event
- Head Office attention to an issue
- awareness of local issues through case conferences.

As an example of how systemic advocacy was initiated in one case, an advocate noted:

> *"One patient inquired about Workers' Compensation for an injury received in one of the workshops. After a little exploration, I found out this was a general issue".*

There were wide variations amongst the advocates in terms of the degree to which they initiated systemic advocacy. At one end of the spectrum, an advocate cited work on eight new issues and a total of 19 or 20 systemic issues during the past year. At the other end of the spectrum, two advocates reported no systemic issues in the past year. Advocates who did little or no systemic advocacy noted the main reasons were a lack of a sense of priorities and lack of time.

> *"These issues are complex. There are so many of them. Some of them have been around for years. It is hard to know what to tackle first".*

> *"You tend to just get caught up in the day-to-day things. Sometimes you need concentrated time to work on these issues. It is hard to find."*

Other reasons cited by advocates for not doing more systemic work included "plain negligence" and lack of direct Head Office support for this type of work. Head Office, on the other hand, emphasized that they often initiated and monitored systemic cases, but have had few resources to do this as effectively as they would like to.

Strategies and Activities. As noted in Table 8, advocates utilized a variety of methods in developing a strategy to deal with a systemic issue. Most advocates reported using informal methods, such as discussions with other advocates, as well as a more formal process of reporting to, and consulting with, Head Office.

Advocates and Head Office have used a range of activities to pursue their advocacy strategies and these are also outlined in Table 8. As an example, four advocates have reported being successful in utilizing hospital committees as a way of implementing new hospital policies. Head Office enlisted the support of other groups as one of its major activities. PPAO briefs to the Ministry of Health have also been used on a regular basis.

Facilitators of Systemic Change. The major facilitators of systemic change identified by advocates and Head Office were support from the Ministry of Health and co-ordination with other groups. The Ministry of Health provided information and contacts, and on some issues, leadership. Other groups who have co-operated in systemic change included: hospital committees, the Ombudsman, the Human Rights Commission, police, the Advocacy Resource Centre for the Handicapped, and community groups.

The perception that the Ministry of Health has been helpful in some systemic cases must also be understood in a larger context. In Chapter VI on Structure, we explore Ministry co-operation as it relates to access to information and independence of the PPAO.

A few advocates suggested that the gradual education of health professionals has facilitated systemic change. At a minority of hospitals, advocates felt that because of creative hospital leadership, change was easier to accomplish with some of the newer graduates in the health care professions. Some advocates suggested that systemic change was also enhanced by taking advantage of the political climate, using a window of opportunity, or building on a current trend.

Barriers to Systemic Change. The most frequently mentioned barriers to systemic change were internal to the program. Three major barriers were cited.

First, most advocates mentioned that there has been little or no accountability to Head Office for systemic work. While the advocates are required to provide monthly statistics to Head Office regarding individual cases, there was no recording system for systemic work. Any knowledge of local systemic issues by Head Office was purely incidental. Advocates indicated that they do not know how much time to spend on systemic work and they tended to respond to the urgency of individual cases first. This tendency for individual casework to dominate has been noted as typical of advocacy programs, particularly programs which are internal to a government Ministry (Wilson et al, 1977; Wolfensberger, 1977, Ziegenfuss, 1984).

Second, advocates noted that there was limited Head Office co-ordination for systemic work. We also identified some issues which

Table 8

Systemic Advocacy

INITIATING	One Patient or Group of Patients	Nursing Staff	Patients and Staff	Government Reviews e.g., ECT	Legislative Committees e.g., Bill 7	Hospital Admin. Studies	Case Conferences		
DEVELOPING A STRATEGY	Gather Information-Facts, Attitudes Supports, Barriers			Check with Other Advocates		Check with Head Office	Identify Key Players		
	Report Back To Initiator			Get Instructions If Necessary					
ACTIVITIES	Letters/ Memos	Brief	Monitoring/Data Collection	Legal Test Case	Negotiation	Media	Petition	Hospital Committee Work	Enlist Other Support Groups, People
OUTCOMES	Policy/Law Changed or Developed	Procedures/ Behaviours Changed	Partial Change in Desired Direction	No change	New Strategies Developed				
	Follow up/ Monitoring	New Allies Identified	Nurture change and try again						

have been pursued in a number of local hospitals, apparently quite independently. Wearing pajamas was such an issue. Advocates tended to circulate memoranda to their colleagues or phone each other to find out who had successful strategies for a particular local issue. According to advocates, Head Office was unlikely to call an advocate to inquire about the progress on a local issue.

Head Office has tried to co-ordinate provincial issues and in some cases has carried out a highly organized campaign throughout the system. But there has been no one Head Office staff person assigned to systemic work, and this has limited the capability of Head Office to initiate and respond. This problem is also in Chapter VII - Internal Organization and Resources. We have also noted that Head Office has recently initiated systemic advocacy in the areas of housing and abuse. The new coordinator has noted that:

> *"Advocates had difficulty in initiating and organizing all the possible systemic cases. By focusing on two major areas, we can support them to become involved."*

The third barrier to systemic change, which was identified by advocates and Head Office, was a lack of protocol or process on how to "problem-solve" a case, monitor events, and follow-up.

> *"A deficiency of the program is that there is no clear way to escalate an issue... no way to proceed and monitor an issue. Things get lost and are left at loose ends"*

Again, Head Office noted that in the current pilot project, mentioned in Chapter III, a protocol was being developed which will give the advocates a stronger sense of how to conduct systemic advocacy.

In spite of these barriers, advocates were generally optimistic about the potential for systemic change. Only one advocate who had not done any systemic work in the last year identified external barriers to systemic change. This advocate suggested that local hospital differences in staffing and facilities, geographic differences, and poor leadership in hospitals were barriers to province-wide change. In addition, this advocate noted that the institutions are traditional and slow to change.

Local Systemic Issues

Local systemic issues centred primarily on therapeutic and social concerns. Legal/legislative issues tended to be provincial concerns. As Table 9 shows, social and therapeutic issues have focussed on ward and workshop procedures or policies, the whole hospital, and the community. Some issues originated at the ward level and became concerns of the

Table 9

Examples of Local Systemic Issues

Issues	*Type**	*Ward*		*Hospital*	*Community*
Telephone Access	S	X	→	X	
Open Doors on Wards	S-T	X	→	X	
Access to Showers	S	X			
Patient Privacy	T	X			
Pyjamas for Control on Ward	T	X	→	X	
Appearance at RRB in Pyjamas	S-T-L			X	
Patient Abuse Investigation Policy	T-L			X	
Pin Money - Need for	S-T	X	→	X	
Administration of WCB Compensation for Work-Shop Injuries	S	X			
Rates of Pay in Workshops	S	X		X	
Developing a Patient Government	S			X	
Quality of Boarding Homes	S			X	X
Community Housing for Forensic Patients	S-T			X	
Sexual Assault Investigation Policy	S-L			X	
Outdoor Access for Patients	S-T			X	
Improved Dental Care	T			X	
Food Service	S-T	X	→	X	
Wheelchair Access to Buildings	S	X			
Privilege System	S-T	X	→	X	
Community Resources for Ex-Patients	S-T				X

---

* Type -
S = Social
T = Therapeutic
L = Legal

whole hospital. One issue originating with one patient in a workshop resulted in a provincial policy for workshop safety.

Table 9 shows the variety of issues advocates have dealt with through a systemic process. It is by no means a complete list of issues advocates have addressed, but illustrates how a local systemic issue can be limited to a ward or include the hospital and the community. Three case studies of local systemic issues are included in Appendix D to illustrate the different types of activities involved in the complex process of systemic advocacy. These cases illustrated the following kinds of local systemic issues:

- Workers' Compensation Benefits - a single patient complaint resulted in clarification of WCB policy for all workshops in the province.
- Pyjamas - a group of well documented cases led to changes in hospital policy.
- Patient government - a patient complaint was quickly solved, but the advocate used the experience to promote self-advocacy by patients.
- Patient restraints on an aircraft - the way in which an issue was approached by the advocate influenced the results.
- Community housing for forensic patients - a non-instructed case illustrated problems in developing systemic strategy and the cross-over between hospital and community issues.

Every case involved careful documentation by advocates and included the involvement of others, primarily hospital staff. The actual strategies used, as shown in Appendix D, varied considerably.

Impact of Local Systemic Advocacy. The impact or success of local systemic advocacy is difficult to assess. In some cases, policy documents confirmed successful cases. For other issues, such as open wards and pajamas, observation indicated success. But for some issues, the results were not as clear for two reasons:

First, many of the systemic files that we examined were incomplete. One advocate, on moving to a new hospital, commented:

> *"When I arrived I found one huge file called 'Issues'. When I sorted, filed, and organized it all in time sequence, it turned out there were 20 distinct systemic issues all mixed together."*

Action on systemic cases is sometimes sporadic and only very diligent advocates keep full records of these cases. Some local cases have been in progress for three years and are still not complete.

Advocates are very rarely the only participants in the change process. Allies have been essential. Many of the system issues we examined have festered in the system for years and have come under sporadic attack from a variety of sources. How can one determine that the advocate played a significant role in the change process? Second, a traditional problem for any evaluation is that of attribution. Would the systemic change have occurred if there had been no advocate? How responsible is the program for the change? Attribution is difficult to assess in this context because there is no expectation that the advocate should act alone or be solely responsible for systemic change.

During our interviews with staff and the advocate, we pursued this question carefully. For each case described, we asked respondents to judge the significance of the advocate's involvement. We credited the advocate with a significant role in the change process when respondents concurred that the advocate played an essential role in promoting the change. Eighteen local systemic cases were randomly chosen and carefully documented by our researchers. In seven cases, the advocate was clearly successful in obtaining the desired change. Two cases were partially successful. Only two cases were clearly unsuccessful. Seven cases were still in progress.

Systemic change in the mental health system is a slow process and most advocates are patient and persistent. Systemic files were rarely closed unless the outcome was successful. We suspect that the two unsuccessful local cases that we examined will be re-opened in the future when new strategies for change become apparent or when a "window of opportunity" opens.

Provincial Systemic Issues

In this section, we discuss issues that involve psychiatric patients in the province-wide health system. Case studies illustrating these issues are included in Appendix E.

Identification of Province-Wide Issues. Each advocate reported issues arising in his/her hospital at the PPAO case conference held every six weeks. Through this process, it often became apparent that some systemic issues were province-wide. When this was the case, Head Office sometimes became active in co-ordinating activities around the issue. Examples have included restraint and seclusion practices, and transfers to Oak Ridge.

Usually, a sub-committee of advocates was formed to research and work on the issue. Head Office co-ordinated the assembly of data and assisted in preparing documents, briefs or submissions.

Relatively few social or treatment issues became province-wide concerns because each hospital had independent policies and procedures. This meant that most social or therapeutic issues were dealt with at the individual hospital level.

Legislative Issues. As noted in Chapter I, the existence of the PPAO coincided with the introduction of major changes in mental health legislation in Ontario and with the introduction of the Canadian Charter of Rights and Freedoms. The PPAO has been very active in supporting the new mental health legislation and in identifying test cases to appropriate legal counsel. This activity has been the main focus of Head Office which employs a full-time legal counsel who has served to co-ordinate the efforts of advocates in pursuit of legislative reform.

Legislative changes are introduced by the government, but the PPAO has played a significant role in shaping legislation and seeing it through to proclamation. A notable example was the contribution of the PPAO in supporting the proclamation of Sections 66 and 67 of the Mental Health Act. Recently it has participated intensely in the discussions on Bills 7 and 190 to amend the Mental Health Act. The PPAO has contributed formal legal counsel and the organizational skills required to bring interest groups together around these issues. Since few lawyers have expertise in mental health law, special legal counsel is an important resource to the program, as well as to the broader community.

At all times, in provincial systemic work, the PPAO has represented the patient's perspective, a view not otherwise well depicted at this level of discussion.

> *"Our power does not come from one person or political power. It is because we are involved with the patients and understand the institutions. Our involvement affects the way change occurs. We take it out of the legal sphere and broaden it to include the practical, human implications for our clients. We are the only ones who can do that."*
>
> *(head office)*

The unique contribution of the PPAO has been their ability to document actual cases because of their ongoing presence in each hospital. Much of the recent legislation has centred on professional practice and procedures in psychiatric hospitals. Hospital staff, especially physicians, have challenged legislative reforms on a number of grounds. The patient point of view has often been represented by advocates, who have presented concrete evidence, through their case work experience, of the patient's perspective and needs. Head Office and the Ministry emphasized that the PPAO's insistence that patient data be part of the legislative debate has brought a new balance to negotiations between the government and health professionals regarding mental health treatment.

> *"They tell me a lot about the real patient issues. I get clues about the changes that are needed when I examine the patterns in the individual cases they handle. That's been very helpful in getting the legislation in place."*
>
> *(Ministry of Health)*

The PPAO has also been active in promoting rights that are guaranteed by the Charter of Rights and Freedoms. In 1985, the PPAO collaborated in a well co-ordinated effort which resulted in securing voting rights at all three levels of government for institutionalized psychiatric patients.

Provincial Policy. Advocates and the PPAO have also been active in framing provincial policies.

> *"The patient advocate in (one area) identified abusive treatment. That process spearheaded the ECT review."*
>
> *(Ministry official)*

This review was considered "ground breaking" by some.

> *"For the first time, clinical and legal standards were developed together by a multi-disciplinary group. Now the Minister has announced a similar process to review issues related to competency. We need more of this type of work -- bringing everyone together and hammering it out."*
>
> *(head office staff)*

At present, hospital administrators are reviewing all hospital policies for compliance with Bill 7 and the Charter. When this process is completed, the PPAO will bring its legal expertise to bear by reviewing the results and commenting to the Minister.

Beyond the Ministry of Health

Some systemic issues went beyond the Ministry of Health. An example was the issue of a comfort allowance for patients.

Each hospital, indeed each ward, has been frustrated by this issue for many years. But there was never any base from which to tackle the issue. It consumes staff and patient time daily and has been a major source of contention between staff and patients. Part of the problem was that the solution required action beyond the Ministry of Health, since the comfort allowance involved the Ministry of Community and Social Services.

The PPAO has the capability to reach beyond the Ministry of Health. Through a co-ordinated effort, including careful documentation of patient cases, the PPAO has brought this issue to the attention of the Ombudsman, the Ministry of Community and Social Services, and the Cabinet. In this case, hospital staff supported these efforts. The PPAO has been the vehicle for achieving something previously inhibited by the structural and organizational constraints of the hospital system.

A decision on this issue is currently on the political agenda and the PPAO continues to monitor the case.

Characteristics of Provincial Systemic Activity

A review of the issues illustrated in Appendix E reveals a number of common features in provincial systemic advocacy.

First, several issues existed long before the Advocate Office began and have been on the PPAO's agenda since its inception. Some are still not resolved. These issues take a long, concerted effort to reach a conclusion. They must be monitored during periods of inactivity due to external events.

Second, the major role of the advocates has involved the documentation of cases and research in the hospitals. In one case (comfort allowance), the advocates were able to get information that the Ministry of Health could not get because the advocates were on site. The persistent generation of documented cases from the advocates reduces the likelihood that an issue can fade into obscurity over time.

Third, the major roles of Head Office include legal research, building and maintaining alliances with other groups, communicating with Ministry and other government officials, acting as spokespersons for the media, and assembling documentation. Many patients' rights organizations, and indeed the hospitals themselves, do not have a central group to co-ordinate activity on issues. Nor do they have expertise on mental health law. These PPAO resources have been significant facilitators of province-wide activities. It has also been important to use a central PPAO spokesperson and communicator.

The primary leadership on provincial systemic issues has been assigned to the Provincial Co-ordinator. While the Co-ordinator should be the major contact and spokesperson for the Advocate Office, s/he does not have time to do the day-to-day research and monitoring of systemic issues.

Fourth, nearly all province-wide issues have involved alliances with other interest groups, such as the Canadian Mental Health Association and the Advocacy Resource Centre for the Handicapped. Each brings different skills to the enterprise. The unique contribution of the PPAO is the documentation of cases, in-hospital research, and representation of the patient view.

Fifth, one or two advocates were leaders in each case that we examined. The special interests, skills and backgrounds of advocates are tapped through sub-committees that work with Head Office. Individual advocates contributed draft strategies, legal reviews, draft letters, and literature reviews on cases in which they had special expertise.

Sixth, systemic files are incomplete. It was extremely difficult to document cases completely. Since these cases go on for several years, it is unsatisfactory to rely on the organizational memory. We suspect that several systemic issues have been "lost" because of poor recording, inadequate documentation and poor co-ordination.

Summary

The systemic advocacy process identified by advocates and Head Office is characterized primarily by wide variability as to the roles played by advocates. Some advocates initiated and co-ordinated a wide number of local systemic cases, while other advocates did little or no systemic advocacy. Given the PPAO goal, "to investigate alleged incidents and assess institutional and system responses to them," our data indicates that some advocates achieve this goal more effectively than others.

The Head Office has been very effective in pursuing legal advocacy, but to date has done little with therapeutic or social advocacy at the provincial level. The PPAO has developed strong alliances with other groups in carrying out most of its provincial legal advocacy. Internally, Head Office has not had a coherent, systematic approach to supporting advocates to pursue systemic cases. Head Office has been aware of this difficulty and their recently initiated pilot project is an important step toward a more effective systemic advocacy process. Our data strongly suggest that the PPAO will need additional resources to expand their initiatives and effectiveness in this area.

RECOMMENDATIONS

1. The PPAO needs to more clearly articulate the role of systemic advocacy and non-instructed advocacy within its mandate.

2. A full-time co-ordinator for systemic and policy issues should be added to Head Office staff; the co-ordinator needs to have skills in the areas of research, policy analysis, and strategies for change, as well as knowledge of psychiatric institutions, the broad mental health network, and government structure and processes.

   The role of the co-ordinator would be to:

   - develop a protocol or process for escalating systemic cases, monitoring events, and following up systemic issues.
   - develop guidelines for the documenting and monitoring of systemic files for local and provincial isses.
   - assist in the development of guidelines for non-instructed advocacy.
   - organize papers, policies, and other materials so that they can be made available quickly to advocates.
   - be aware of all local systemic issues for the purpose of linking advocates with others who have expertise on particular issues.
   - provide research and analysis support for both local and provincial issues.
   - assume leadership, with the Provincial Co-ordinator, in representing the PPAO's policies to external groups.

3. Comprehensive strategies and principles need to be developed which would increase the effectiveness of non-instructed advocacy; this requires that the PPAO:

   - further develop guidelines for the non-instructed advocacy process and methods of appropriate interventions related to non-instructed cases.
   - collaborate with other voluntary associations to develop guidelines and suggestions for advocates on how to monitor psychogeriatric and mental retardation wards.
   - develop strategies with advocates to more effectively link non-instructed cases with systemic advocacy.

Chapter V

IMPACT

This study revealed that the PPAO program has had a significant impact on many groups and individuals. Some of the impacts were positive, some negative, some intended, and others unintended. It is no surprise that people perceived some of the impacts to be positive and some negative:

> *"Whenever advocacy really begins to work, it will be persecuted, because it will be a threat. Conversely, the phonier an advocacy or protective system is, the more likely it is to be praised, legitimized, exalted and funded (Wolfensberger, 1977, p. 49)."*

Many of our findings were concrete and will be able to guide judgments about the future role, structure, powers, and independence of the program, as well as its transferability to other contexts. Other findings were less clear and more contradictory and will need further study or investigation.

Impact, in a positive sense, refers to whether or not the PPAO has been a stimulus for positive change. In negative terms, impact encompasses deleterious effects, which can be attributed to the introduction of the PPAO. In institutional settings, however, issues are complex and are affected by various factors and broad historical trends. Accordingly, several reasons have complicated the assessment of impact:

- Because all 10 provincial psychiatric hospitals have advocates, there was no control group comparison.
- A 7 month study did not allow time to do pre-program baseline comparisons.
- Many confounding variables impacted at the same time on the mental health system e.g., Charter of Rights, Bill 7, Bill 190.
- During a 7 month study of a 3 1/2 year old program it is difficult to distinguish temporary from long-term and systematic changes.
- On many issues, advocates did not work alone, and it was thus difficult to make judgements concerning attribution.

- Much of the statistical data kept by the PPAO have not been very helpful in assessing impact.

In some cases, documentation made it possible to determine that an impact was real. Most often impacts could be assessed only according to perception. It is usual for social impact studies to assess concrete changes, but nevertheless, perceptions of impact constitute an important aspect of impact(Willets, 1981). Even though it has been difficult to ascertain attribution to the PPAO, projects are often local manifestations of a more general historical trend. Accordingly, most social impact studies take into account the more generalized processes of change which are occurring in society at any one time (Bowles, 1981). Therefore, referring to literature on the impact of other advocacy projects and on broader mental health changes has been one way of comparing and contrasting the impacts of this project.

Social impact studies also assume a program has more or less stable patterns, but this was not always true in this study where so many different sites, each operating relatively independently, were studied. While a strong attempt has been made to find general patterns in the overall program, exceptions are important to note. They can provide clues for planners in thinking about future directions (Bowles, 1981).

The purpose of studying impact of a program then is to: protect positive impacts; ameliorate current negative impacts; avoid future negative social impacts; assess unintended impacts; and work towards the development of other positive social impacts. This requires links between project characteristics and changes in social conditions. Another aspect of impact is also to predict future impacts so as to uncover irreversible negative effects or impacts before they happen (Bowles, 1981). Thus, in this chapter, several aspects of impacts will be presented:

A. Impact on Individuals
B. Impact on Staff
C. Major Issue Affecting Individuals and Staff: Rights Versus Treatment
D. Impact on Hospital Dynamics
E. Impact on Policies

A. IMPACT ON INDIVIDUALS

In each of the major sectors surveyed in the study, there were feelings that the PPAO has had both positive and negative impacts upon individuals. Staff (doctors, nurses and social workers), while noting positive impacts on attitudes and rights, were generally negative about the impact of the program on patients. This is consistent with the literature, in which psychiatrists, in particular, have been negative about other advocacy programs (Hilliard and Gutheil, 1981; Hoaken, 1986; Lamb, 1981). Table 10 below summarizes the staff's perceptions of the positive and negative impacts on individuals.

Table 10

Positive and Negative Impacts of the PPAO on Individuals

Positive	Negative
• increase in patients' rights and their enforceability	• increased opportunity for patients to refuse treatment
• improvement in patients' and staff's awareness of rights	• earlier discharges
• assurance, support & protection for patients	• longer periods of institutionalization
	• fear of retaliation against patients

Positive Impacts

For the most part, the major sectors agreed that there has been an increase in actual rights for patients, as well as in the enforcement and awareness of those rights. Respondents often described improved rights with terms like 'better rights', 'less abuse', or 'less illegal action'.

Actual Rights. A few families, several patients at half the hospitals, and most advocates and administrators felt that the advocate program has made a significant contribution to improving the rights of patients. Generally, people meant that patients' ability to exercise their rights had improved.

> *"There has definitely been an overall improvement in rights as the result of the PPAO. Voting privileges are improved; single ex-psychiatric patients may now live in public housing; people are now aware that they have rights and can exercise them; we helped give the last push to get rid of the behavior modification unit." (advocate)*

> *" The advocate has made people think about rights... the old approach was clinicians working in the best interests of patients. There was a tendency for clinicians to be on the side of safety and control." (administrator)*

A minority of the staff in each setting from each group interviewed, and most of the advocates felt strongly about the improvement in exercising rights, but made no attempt to attribute impact to the PPAO. They did not seem to care what caused the improvement, as long as it happened. Their comments were reflective and insightful.

> *" Rights have improved. The ones that aren't getting their needs met are speaking up more... Doctors who are more brisk with patients are more aware now and involve the patients more... the nursing process involves the patient more...we don't have as free a hand as we did ten years ago. It used to be a 'slam bam-give an injection' - now we have to think about it more." (nurse)*

> *"The patient government represents their own values and issues, their own sociology. They are beginning to achieve a whole other life, other than staff's life. Staff are rethinking things, and patients are standing up." (advocate)*

Many nurses and social workers, almost half the psychiatrists, and some of the advocates agreed there was an increase in rights. However, they felt that it was largely due to legislation, the political climate, the media, and other factors, rather than the advocate program alone.

> *"My guess is that a lot of it was in process because of the American literature on this in the 60s and 70s. The American legal system brought down ground breaking rules in the 70s regarding the right to refuse treatment and the inhumane system. The PPAO has implemented patients' rights, but is not responsible for improvements in patients' rights. The PPAO may be a mechanism for ensuring compliance." (medical director)*

> *"Staff here tell me there's been significant change, mainly due to the Mental Health Act. Treatment issues have been sharpened and patients are learning to relate to the Act. Awareness is way up." (advocate)*

It is noteworthy that many respondents felt there were a number of factors which had increased patients' ability to exercise their rights. It may be that the PPAO simply embodies current social and legislative developments.

The last quotation from the advocate, in particular, relates in an interesting way to the literature. Historically, people labelled mentally ill have been perceived as a minority group and have been denied basic civil liberties. Now this is changing; increasingly people see themselves as part of the consumer movement which is aiming to improve quality of life, services, and rights (Wald and Friedman, 1978).

Awareness of Rights. Many patients, advocates, rights advisors and staff felt that there has been a tremendous increase in awareness of rights by both staff and patients, attributable to the advocate program.

> *"People watch more now, patients are more aware of their rights, they use the advocate more."* *(client)*

> *"The program has made all of the clinical staff aware that patients have rights."* *(social worker)*

> *"Patients have told us they were here years ago and that it's better now. The advocate office makes a difference, having an actual person explaining it to you."*
> *(rights advisor)*

While staff in general noted an improvement in awareness of rights, noticeably fewer psychiatrists (2 sites) mentioned changes, compared to nurses (11 sites) and social workers (7 sites).

Many comments about improvements in attitudes showed a recognition of the changes, but did not attribute them to the advocate office or anything else in particular.

> *"We've learned to speak up and have become more independent."* *(client)*

> *"You don't see the old fashioned, patronizing attitude of staff- there has been a tremendous change in attitude."*
> *(psychiatrist)*

> *"There's a different calibre of patient than we used to have - that is, short-stay patients who haven't been institutionalized as long and who are more aware of their rights."*
> *(nurse)*

> *"There is a heightened awareness that has assisted us to allow patients more individual freedoms. This has given us*

> *permission to let patients take responsibility, and the risks of involvement."* (nurse)

Finally, a few staff members again made a point of attributing changes to several social factors, one of which may be the PPAO.

> *"It has heightened awareness of patients' rights. Authoritarian staff are more aware that those attitudes are unacceptable - I'm not sure how much is due to the PPAO. There are lots of other changes - education, societal attitudes, younger staff."* (nurse)

All staff except administrators were given a knowledge survey as part of this study. 80.5 % of staff indicated they believe that their knowledge of human rights has significantly increased in the last three years and 16.4 % said it has not. In Table 11 below you will see the reasons they gave for this improvement. These findings showed that staff felt that the advocate had made a significant contribution, particularly when you added items no. 3 and no. 5 together. As well, several of the advocates have had involvement with no. 6 and possibly no. 9.

Table 11

Factors To Which Staff Attributed Their Increased Awareness of Patients' Rights

	Factors	**%**
1.	Mental Health Act	22.0
2.	Learning through job responsibilities	16.0
3.	Contact with the advocate	13.0
4.	Media, including professional journals	13.0
5.	Written information from PPAO and Ministry	11.5
6.	In-service education	8.5
7.	Charter of Rights	6.0
8.	Self-education	6.0
9.	Direct experience with patient complaints	4.0

Assurance, Support, and Protection. Several patients in more than half the sites and a few advocates were the only ones that mentioned that an important impact of the program was that the advocate represented a place for assurance, support, and protection.

> *"Five years ago things were a lot worse -- nowhere to go with your concerns; attendants would beat up patients a lot. Abuse is less now."* (client)

> *"It's good to have someone to go to who is confidential and won't go to the nurse and talk about it, unless you tell her to; you can tell them what's happening and not worry."*
>
> (client)

> *"A lot of times when a patient is angry, you need an outlet; staff won't listen or you get blamed; whether successful or not, the advocate is a place to go to problem-solve."*
>
> (client)

A former patient at a community meeting emphasized that patients need to be able to ask about rules without *the asking itself* being treated as a symptom. This unintended impact of the PPAO from the patients' point of view raised questions about how to best structure an advocacy project so that assurance, support, and protection are features.

Other Outcomes. A variety of individuals mentioned several changes that suggested that the PPAO had had a positive impact. These changes included: the advocate being able to obtain resources for patients, fewer restraints being used, the mandate to treat sooner, and increased privileges. Still, it was not clear, at least for the latter three issues, if staff felt they were the result of the PPAO or broader changes in legislation and attitudes of society.

A Survey. Staff completed a written questionnaire and were asked to rank the Advocate Office in terms of its benefit to patients.The results of this survey are presented in Table 12 below.

Table 12

Staff Ratings of the Advocate Office in Terms of Impact (Benefit to Patients)

	Overall (%)	Without Oak Ridge (%)
very positive	15.1	17.3
somewhat positive	27.3	28.9
neutral	15.1	16.5
somewhat negative	22.3	19.8
very negative	3.6	.03
did not respond	16.5	14.8

From these results, it can be seen that without Oak Ridge, over 46% of the staff have 'somewhat positive' and 'very positive' feelings about the impact of the PPAO on patients. Approximately 16% were neutral, another 14 % did not respond, and the final 20% were 'somewhat negative' or 'very negative'. The results reported below provide some idea of the reasons for the staff's negative feelings towards the PPAO. The data illustrated that staff at Oak Ridge were more negative than at any other site.

Negative Impacts

Staff (psychiatrists, nurses, and social workers) agreed on three negative impacts of the PPAO on individuals. All of these perceptions represented minority views. As well, a minority of patients identified one significant negative impact.

Increased Opportunity for Patients to Refuse Treatment. While staff in all sites mentioned this issue, nurses (5 sites) most noticeably focused on the issue as compared to psychiatrists (1 site), and social workers(1 site). Since the nurses are usually most accountable for the day-to-day treatment of patients, perhaps it was no wonder that they would feel this impact most strongly.

> *"Patients have too many rights, especially refusing treatment when they need help and cannot make rational decisions. If patients can refuse treatment, then why are we here? Are we a holding tank?"* *(social worker)*

> *"There's more aggression and more seclusion now because people are opting not to take their meds. Years ago we had total control; now it's gone the other way to almost no control. Patients threaten us by saying 'if you don't do this, I'll go to the advocate.' The right to refuse medications has had negative effects."* *(nurse)*

In many of the comments, staff related patients' right to refuse treatment to the staff members' loss of control, suggesting an unintended consequence, which relates to the sub-culture of the institutional setting. Interestingly, in the interviews with the Regional Review Boards, 7/9 said they received very few applications to issue treatment orders. A recent study of Regional Review Boards in Ontario showed that a significantly greater proportion of applications for decertification [from patients] are refused by RRBs than are applications from psychiatrists seeking patient treatment (Chandrasena and Smith, 1986). In other words, the RRBs generally uphold psychiatrists' desire to maintain treatment.

Patients are Institutionalized Longer. A minority of staff, especially nurses (3 sites) as compared to psychiatrists (1 site) and social workers (1 site), perceived that patients often end up being institutionalized for longer periods of time because they refuse their medications, as discussed above, and therefore stay sick longer and require longer hospitalizations. This issue was simply not mentioned at most sites.

> *"I know of people who have spent long periods of time in here -six months to a year - because of the right to refuse treatment."*
> *(psychiatrist)*

> *" From the patients' point of view, the advocate is probably helping them, but then again they are patients. They probably think its better not to take their meds, but they stay longer."*
> *(nurse)*

This issue raised the questions of whether compliant or non-compliant patients "get better faster". Hassenfeld & Grumet (1984) have suggested that non-compliant patients may stay in the hospital longer before released but also stay longer in the community before requiring re-admission.

Patients are Being Discharged Earlier. Staff in only one site, for each of the professional groups, mentioned this impact, as well as a few families and Review Boards. While this issue was mentioned by only a very small minority of respondents, it still presents an interesting contradiction to the previous issue. Can it be that the Advocate Office and other legislative changes produce both effects: causing some people to stay in hospital longer (because they won't take their medications) and permitting other people to get out too soon?

> *"They (the advocate) make the Review Board a political process. That's not why it's there. Sick people are used as pawns in a political game run from Head Office."*
> *(psychiatrist)*

> *"Staff are fed up with the way some patients are using the system. We used to persuade them to stay if we felt it would be in their best interests, but now we don't bother as much. There are people with behaviour problems who come in 2 to 3 times a week - they sign out at 4 p.m. and are readmitted at 3 a.m. in a crisis."*
> *(nurse)*

Although not specifically attributed to the PPAO, several people at community meetings noted that people are being discharged earlier without proper discharge plans and community options in place.

Fear of or Actual Retaliation. A minority of patients at six sites mentioned fear of, or actual retaliation. Their perceptions showed that they felt that if they used the advocate, they would suffer some kind of repercussions from staff. Most of these patients were from forensic units.

> *"The staff person is now scared of me. He's trying to get other patients to punch me out. He's a shit disturber and he likes to cause trouble."* *(client)*
>
> *"I'm afraid to use the advocate and afraid of the doctors' resentment if I want out."* *(non-client)*
>
> *"Use it as much as you can but be prepared to be punished if you do."* *(client)*
>
> *"I know I have rights and if something is wrong, I complain to her. The staff say you're an informer, a rat if you go to the advocate."* *(client)*
>
> *"Sometimes people are afraid; after I went they gave me ECT; the advocate tried to stop it but couldn't."* *(client)*

Summary

Our data concerning the impact on individuals showed that a majority of staff, advocates, patients and families felt the PPAO was having a very important and significant impact on staff's and patients' awareness of patients' rights. Many people also believed that the PPAO has had an impact on patients' ability to actually exercise their rights. While many people qualified their statements, giving credit to broader trends and legislation, most agreed the advocacy program at least has helped ensure that patients can assert their rights and be more aware of the rights of others.

At the same time, a majority of staff identified negative impacts of recent legislation and the Advocate Office, including patients' increased opportunity to refuse treatment which leads to longer hospital stays for many people.

The greatest negative impact from the perspective of a minority of patients was the fear that they may actually suffer retaliation from staff as a result of being involved with the advocate. Some people reported concrete examples which they felt were directly related to their involvement.

Finally, both advocates and staff agreed that the Advocate Office has not had any noticeable impact on many people who need it the most: those individuals who are less articulate and less independent, such as the elderly and non-English speaking people. This confirms our findings in Chapter IV on non-instructed advocacy.

B. IMPACT ON HOSPITAL STAFF

Most staff, administrators, advocates, and rights advisors felt that the PPAO has had a significant impact on the staff in the hospital. The major areas in which people felt the advocacy program has had an impact on staff are:

- in its role as a resource.
- in its effect on the use of staff time.
- in its overlapping role.

Only the first area was perceived by all groups generally as having had a positive impact. People's perceptions of the PPAO's impact on the other two areas were, at best, mixed. See Table 13 below for a summary of the positive and negative impacts on staff.

Table 13

Positive and Negative Impacts of the PPAO on Staff

Positive	Negative
• advocate as a resource -explaining rights -pacifying patients -giving legal advice (to staff) -informing admin. of problems with advocacy (staff)	• extra time spent on paperwork & related activities -preparing for Review Boards -covering self legally through charting -legal self-protection
• not everyone's time was affected	• erosion of role of staff as advocates
• overlap in roles seen as a support	

Positive Impact

Advocate as a Resource

The most positive overall impact on staff was in the area of the PPAO being available as a resource. A majority of social workers were most positive (7 sites), along with half the administrators. A minority of nurses at six sites and psychiatrists at four sites also viewed the advocate as a positive resource. These findings made sense, since as we will see in the next section, social workers perceived some overlap of roles with the advocate and therefore were most likely to appreciate the advocate's role as a resource. Social workers often defined themselves as "problem-solvers" and in this regard might use the advocate office to help solve problems. Conversely, psychiatrists were least likely to "problem-solve" with the advocate and would therefore be the least likely group to draw on the assistance of the Advocate Office.

Hospitals with less adversarial advocates were more likely to consider the advocate as a resource, although it was also mentioned in two hospitals where the advocate was more adversarial. These data link with our effectiveness findings in Chapter III.

Examples of some of the ways advocates acted as resources included:

Explaining rights to patients, saving others the time and trouble. Staff agreed that patients needed to be informed of their rights and if the advocate did this, it would relieve staff of this time consuming responsibility.

> *"The advocate's role saves me from telling patients about their rights and I can direct further questions to the advocate who can help them if they are having difficulties."*
> *(psychiatrist)*

> *"The work of the advocate supports the work of the nurses. It relieves them of the duty of explaining rights and non-nurses can do this better anyway. They didn't listen to us anyway. We're the bad guys - we give them medication."* *(nurse)*

Pacifying patients. A majority of staff felt there were many patients who 'hung around' and continually bothered staff with unimportant issues. They were happy to let the advocate take his or her share of this task.

> *"We use the presence of the advocate to get rid of and pacify patients who are bugging us. If we are questioned about their care or hospitalization, we say 'if you don't like it, go see the advocate.' "* *(psychiatrist)*

Legal advice/information source. Some staff saw the advocate as someone who had an expertise on legal issues in particular, not only those of patients, but their own.

> *"Nurses call the advocate when they are unsure about things like how to get legal assistance, and whether a patient will be charged."* *(nurse)*

> *"[The advocate] came on the ward and pointed out to us how we could do something to be more in line with the laws."*
> *(nurse)*

Monitor. Several administrators and directors of nursing saw it as an advantage to have someone who could let them know of things s/he saw on the wards and throughout the hospital that should be investigated. Staff did not see this in the same positive way.

> *"There might be a real problem- some staff person may be doing something they shouldn't and I want to know about it. When I hear of a problem from someone like the advocate, I like to get some information on my own and check it out."*
> *(director of nursing)*

> *"I appreciate the presence of the advocate; I welcome his independent advice since it is hard for the person at the top to get good information. "*
> *(administrator)*

At a broader level, advocates in other jurisdictions have been viewed as people who can inform the system of abuses. For example, in the State of Michigan, the Director of the Department of Mental Health was forced to resign for not taking action over the conditions at Plymouth Centre. A review was initiated by the Advocacy Office and called for by the legislature. Ultimately a district court judge ordered an immediate halt to all new admissions, doubling of staff of certain wards, and the establishment of a monitoring committee (News and Notes, 1978).

Assist with advocacy. A minority of staff saw the advocate as someone who could be used to assist them with advocacy, problem-solving, and effecting change.

> *"One staff didn't like the treatment, the restraints that one patient was getting. The staff person went to the advocate and she helped her to work it out."*
> *(nurse)*

> *"The Ministry has done nothing about accommodation for discharged patients. Our social workers are burned out on this issue. She [The advocate] is really going for it. She really made the difference."*
> *administrator)*

The advocate in this regard was viewed as being in a particularly advantageous position because of their independence from the treatment team.

> *"Her being an outsider may make a difference; it gives her more clout than we have. There are less ties to the team, so it gives her more independence."* *(social worker)*

Not everyone was totally comfortable with using the advocate as a resource, either because of staff alliances, or perceived limitations on the part of the advocate .

> *"I don't refer to the patient advocate because it would feel like betraying the team... How candid can you be with the advocate? As a social worker you are still in the team."*
> *(social worker)*

Negative Impact

Time Use

The impact that the Advocate Office has had on the use of their time is the issue staff felt most strongly about when discussing impact on staff. In particularly, this issue was raised by a majority of psychiatrists (10 sites) and nurses (8 sites). Interestingly, it did not seem to be an issue for the social workers and administrators. Perhaps this was because social workers and administrators were not directly involved with treatment and certification issues. Some administrators and medical directors talked of their role as liaisons between staff and the advocates, but did not seem to view it as a time problem.

The concerns around time that staff had are divided into several areas:

Preparing for and attending Review Boards. Review boards seemed to be a large issue in people's minds. Most psychiatrists acknowledged that legislative changes, not just the Advocate Office, contributed to the impact that Review Boards were having on their working hours. But since most staff assumed the advocate was encouraging patients to use the Review Boards, the two have become synonymous. Primarily, this was a concern for the psychiatrists, because they have had to do the majority of the preparation for Review Boards.

> *"There are many indirect or hidden costs of the advocacy program...in doctors' time; we can't spend time with patients if we are with lawyers and Review Boards. We're so busy defending what we do, we can't do it anymore."*
> *(psychiatrist)*

Inherent in this concern was the issue that if the doctors were spending so much time with Review Boards, they would not have the necessary clinical time to spend with patients.

> *"Our paperwork has increased 20 fold. The Review Board takes at least a full day... I had spent 5-6 hours in a week on a patient but not with him. This patient questioned me on this and so did the family."* *(psychiatrist)*

> *"The Advocate Office has produced work for doctors that takes time away from serious matters."* *(psychiatrist)*

It is interesting to compare these perceptions of physicians and psychiatrists with other data in the study. At two hospitals we examined randomly, RRB applications have remained about the same over the last five years. Also, the PPAO data indicate that fewer than 9 per cent of their cases actually involved RRB hearings. The issue for some psychiatrists however, was that the process of presenting at the RRB hearings has increased in complexity.

Concern for own legal protection. Some staff indicated they have changed their time use in order to protect themselves legally. Nurses were the group most concerned about protecting themselves from accusations and possible litigation resulting from the advocate's monitoring.

> *"It's a shame for staff to be spending creative energy trying to outwit the advocates."* *(nurse)*

> *"We spend more time charting. We used to educate and teach patients but now we defend. We spend time trying to defend and explain what we are doing."* *(nurse)*

> *"We record more of what we do, what happened, the reasons for medication or seclusion, but other things may be left out."* *(nurse)*

On the other hand, some staff tried to chart less to protect themselves.

> *"Staff are afraid to chart because patients can read their files, they assume 'if I don't chart, my name's not on anything, I'm not in trouble.' "* *(Ward Supervisor)*

Not everyone felt that their time had been affected. In group interviews, there was usually one person out of every five or six who disagreed with the group and said there was no negative impact.

> *"Time use has not changed with regard to explaining rights to patients; I have always told them their rights when I put them on a certificate and will continue to do so...Staff have always been very cognizant of rights and legally-minded, long before the advocacy program."*
>
> *(psychiatrist)*

> *"There is no substantial change in how they use their time, but she expects nursing staff to find and get charts for her. Her tone of voice and manner turn people off."* *(nurse)*

Mixed Impact

Role Overlap

Advocate role being eroded. The most noticeable concern of staff was that their advocacy role was being eroded by the advocate. They seemed hurt and offended by a process which they believed endorsed overlap in roles. These data link with staff views that they are the primary advocates for the more vulnerable patients, already discussed in Chapter IV on Effectiveness.

> *"In nursing, advocacy is part of my role, but I am made to feel that I'm not doing it.... the nurses spend all day with the patients. The nurses know the patients the best and now are restricted in our ability to help."* *(nurse)*

> *"I thought we were the real advocates. We're always seen as the bad guy, as jailors rather than clinicians or helpers."*
>
> *(social workers)*

Despite the fact that social workers appreciated the advocate's role as a resource, they also felt most strongly that their advocacy role was being eroded (7 sites). Nurses also complained strongly of role erosion (6 sites) but psychiatrists were only slightly concerned (2 sites). Again, these findings made sense, since social workers have historically seen their role as advocates. Nurses, as discussed in Chapter IV, have increasingly been socialized to believe they are advocates, but perhaps have not understood some of the difficulties with doing both service and advocacy. Finally, psychiatrists would not see advocacy as a strong priority in their helping relationships with patients.

Administrators had some of the most interesting comments on role overlaps. One administrator believed there would be unintended negative consequences if roles were too separate:

> *"But if you detach advocacy from the role of each staff, you run a great danger of lowering the human response of each staff to a point where scandalous things happen."*
>
> *(administrator)*

Another administrator indicated that certain negative impacts that he expected have not come to pass:

> *"When the program was new, staff were very concerned. They believed they were advocates and this was a Ministry put down. The scenarios they expected haven't occurred."*
>
> *(administrator)*

In more than half the sites, a minority of patients confused advocates with social workers. Earlier data on effectiveness suggested that, in fact, patients were aware of the advocate as being someone different. While the impact data suggested that patients tried to use the advocate for social work functions this does not imply that they did not realize the significance of the advocate's role.

> *"There is much confusion about roles. Patients confuse all the roles and because of this we try to see if the person has tapped all the natural advocacy of their therapeutic team before using us; if they haven't, I send them back."*
>
> *(advocate)*

> *"When I introduce myself to patients on the ward, they ask if I'm a social worker. When they come to my door, I sort them out and refer them back to social work if appropriate."* *(advocate)*

Several advocates mentioned tensions related to the overlap of roles, but the following quotation raised a slightly different issue: that is, the problem was a lack of respect for the advocate's role, rather than concern about overlap or erosion.

> *"Staff do not see advocacy as a profession; we acknowledge the validity of their roles; now they need to approve of our role. As well, no one is used to seeing advocates function on their own and that's why they don't like it. Treatment people are asked to jail them, treat them and be their friends...it's too much. Nurses are accountable to their profession; we need a profession which is accountable to patients."* *(advocate)*

Overlap in Roles Not A Problem. Not everyone saw the advocacy role as overlapping or threatening. A minority of nurses and social workers who understood advocacy were most easily able to perceive the value of having advocates at the hospital. Although most of the advocates felt that there was some overlap or role confusion with other staff they did not see this as a problem.

> *"We have a broader range of responsibility; we deal with housing, psychology, life skills, whereas the advocate just deals with legal issues; however, the advocate can go further than an MSW and can pull strings; we are under*

> *administrative checks but the advocates are outside the system so not constrained."* *(social worker)*

> *"There is no overlap. The advocate fills a need that a patient perceives is not being met by other disciplines. It's a check and balance."* *(director of nursing)*

> *"Yes, we overlap with staff; but their role ends because they are members of the clinical team and hierarchy. Then we can go further. We pick up when things are not done, due to short staffing or burn-out or not caring, especially discharge planning... the advocates and staff have modified each other. They've taught us a lot and we've taught them."* *(advocate)*

And finally, rights advisors generally felt their position had not created any role confusion and that staff understood the role of rights advisors. The rights advisors in four sites felt that there was some overlap with the advocate on legal aid issues, but that this overlap had not caused any difficulty. Communication with the advocate was seen as a very important aspect of minimizing this overlap.

> *"My role is much clearer than the advocate's to the staff. Nurses feel she treads on their toes. I'm supportive. MDs explain rights when they sign the form, but patients are too out of it. They need to hear it later, and over and over. I do that for MDs."* *(rights advisor)*

> *"Our roles overlap because I do some advocacy. I turn it over to the advocate when it comes time to write memos, or negotiate with staff. I primarily refer people. Or if the advocate is away, she will give me instructions as to who to negotiate with."* *(rights advisor)*

Summary

The most positive impact on staff was that staff saw the advocate as being a resource for themselves. Also, a minority of staff considered the overlap in advocacy role to be a positive impact of the program.

On the other hand, many staff felt very negative about what they saw as a role overlap in the area of staff advocacy. As well, they were resentful about the impact the advocate program was having on the way they spent their time - psychiatrists were having to prepare for Review Boards and nurses were protecting themselves in case the advocate questioned them. A minority of staff believed all of these factors detract from more important things, particularly time with patients.

C. MAJOR ISSUE AFFECTING INDIVIDUALS AND STAFF: RIGHTS VERSUS TREATMENT

The introduction of "rights" into the mental health field has had wide ranging effects (Bloom and Asher, 1982). A strong theme which emerged from our data was that the concept of enforced rights had heightened the "rights versus treatment" controversy in Ontario's provincial psychiatric hospital system. This unintended impact was perceived by a minority of staff to be very negative because "rights interfere with treatment." Patients, however, did not see this conflict. This suggests we need to find ways for advocates and staff to minimize the notions of conflict in this area, whether real or perceived. Several advocates and a small minority of staff had concrete suggestions on how this might be accomplished.

In this section, we briefly present some data illustrating people's perception of this impact, and then discuss the implications in light of other data and the literature.

Rights Emphasized So Much That They Interfere With Treatment

Most of the comments by professionals indicated that rights were emphasized so much that they interfered with the treatment process. Nurses and psychiatrists felt most strongly about this issue (6 sites) as compared to social workers (3 sites) and advocates (2 sites).

> *"Patients are suspicious of treatment and the problem is that the advocate reinforces that belief when s/he says these are your rights. This interferes with treatment and patients end up getting a disservice not a service."*
>
> *(psychiatrist)*

> *"The issue is balancing legal rights with the right to be treated. If the patient was treated s/he could move on faster; if the patient refuses treatment, it can cause great delays in moving the person back to a regional hospital, the jail, or the community. Rather than getting better and moving on, the person remains strapped to a bed."*
>
> *(social worker)*

Patients, however, did not see that rights have interfered with treatment. In fact, no patient raised this issue during interviews. On the other hand, a significant minority of patients noted concerns about treatment not always being appropriate for them.

> *"Their idea of treatment is we're going to try a new drug."*

> *"We need medications with less side effects. Some pills are good, but side effects are a problem."*

> *"Doctors have control. We should have a right to a different (second) opinion. Is it possible to change doctors?"*

Rights Versus Best Interests. This sub issue was a tremendous concern for staff, possibly the main focus of their conflict with the advocates. Basically, staff did not see the advocate's premise, 'taking patient instructions', as being in the best interests of most patients.

> *"There is a difference between the patients' best interests and their rights to the letter of the law. With the advocates insisting that their mandate is to inform the patient of his rights, it creates a pretty conflictual situation with medical professionals who see their mandate as doing what's in the patient's best interests." (psychiatrist)*

By not being able to do what the staff consider to be in the best interests of the person, they feel they are in a no-win situation.

> *"It's negligence if they fall and hurt themselves, but a violation of rights if we tie them down." (nurse)*

Rights But Not Responsibilities. Sometimes staff seemed to be referring to the lack of responsibility assumed by the advocate or whoever else makes the decision contrary to the preference of the clinical team.

> *"It's very difficult to watch patients get sicker and sicker and do nothing. Now a review seems automatic instead of occasional, it shouldn't be...Who is responsible if the Review Board releases a patient against a doctor's advice.?..People have rights and responsibilities." (nurse)*

> *"The advocate advises the person to exercise his rights, but then the advocate is not accountable for the outcome. The nurses are." (nurse)*

> *"Everybody talks about rights but nobody talks about duty. If you have rights, there must be duty that goes along with it, for example duty to behave properly and so on." (nurse)*

Basically, staff felt that the advocate primarily provided only one side of the story: that is, patients have a right to refuse treatment. Staff believed that this tendency of the advocate widened the debate between rights and treatment.

> *"We inform patients of their legal rights, so advocates should inform them of the clinical issues - they only give the legal side."* *(social worker)*

Most staff emphasize that the explanation of rights should be put into perspective by also explaining the potential consequences or outcomes of exercising one's rights.

> *"It should be explained: 'You have a right to refuse, but you may be in hospital longer, and you have the right to accept treatment; you should consider that you may be better off with the treatment.' In other words, there needs to be a balance between the right to refuse, and the right to get treatment."* *(psychiatrist)*

Many staff said the advocates not only tell people they have the right to refuse, but also advise them to refuse their medications or treatment. When asked how they know this, most just insisted that *"they know."*

> *"It is a clinical responsibility to tell patients the impact of a decision. The advocate just says 'go ahead and refuse' and doesn't give the patient any information about what will happen as a result."* *(psychiatrist)*

On the other hand, nurses at one site clarified this issue, saying that while people may in fact be told their rights, they interpret this as definitive advice to exercise those rights:

> *"Telling patients their rights may be contrived as suggestions to act. Knowledge of rights are not directives, but there is confusion here ."* *(nurses)*

> *"Psychiatrists and clinicians are left with the ramifications of people learning their rights; but we believe the right to receive treatment is equally as important as the right to refuse treatment."* *(administrator)*

> *"The delay in sorting out whether or not the patient can be treated cannot be blamed on the advocate; this is the fault of the Mental Health Act. The system is focused so heavily on the right to refuse treatment and it is not focused on their right to have treatment. Regardless, mentally ill people do suffer."* *(psychiatrist)*

But rights advisors and advocates said they gave both sides of the story to clients and did not directly interfere with treatment.

> *"If a patient is psychotic and wants to stop treatment, the advocate discusses both sides of the story - the pros and the cons; but the advocates must always act on their instructions in the end."* *(rights advisor)*

> *"We must tell them their rights, but need to help them to understand the consequences of refusing drugs. On the other hand, it is easier to shoot a person up with drugs; research says those on drugs don't recuperate as fast as those not on them."* *(advocate)*

> *"I can't see it as interfering even if I'm helping someone refuse treatment. I feel that the issue is there anyway. I'm helping the patient articulate it. Maybe I stopped coercion where coercion shouldn't exist. I hope I'm helping people articulate their wishes in terms of treatment."* *(advocate)*

> *"The issue is not refusing treatment, but the desire for alternative forms of treatment."* *(advocate)*

Rights Emphasized to Detriment of the Family. Very few families and staff pointed out the impact that increased rights for patients had on families.

> *"The client's right takes away from the right of families to be free from abuse and confusion."* *(social worker)*

> *"By not proceeding with drugs, patients and families suffer. Their (patients') financial situation is jeopardized as hospitalization is prolonged."* *(nurse)*

> *"I disagree with the Act where a person cannot be made involuntary unless they are a danger to themselves. My mother is in a bad way but is not involuntary and can leave. It might be better if she was a danger. It's terrible it should come to that."* *(family)*

Staff/Patient Relationships

The notion that staff are feeling caught in a 'no-win' situation seems to be a key issue for staff across the province. It's not just that they feel caught between the advocate and hospital administration, but they feel caught between all the legal changes of the Act and a commitment to treat patients. Psychiatrist (6 sites) and nurses (6 sites) felt most strongly about this issue. Social workers (3 sites) mentioned it as an issue but did not give it the same negative connotations.

Rapport/Therapeutic Process. Staff felt that it was difficult for them to maintain a positive, respectful therapeutic relationship with patients when the advocate was continually encouraging the patient to question every aspect of his or her care.

> *"It's very hard to treat an involuntary patient and to build trust. It would be wonderful to have a third person to help, but her role is too adversarial. We just have to wait till it's all over and then try to start a treatment relationship."*
> *(social worker)*

> *"If the civil libertarian premise is that patients need to be protected from doctors and nurses, how can anything be resolved; a fundamental issue here is causing a polarization. How can one be supportive of a situation which creates more anger and frustration when there is already a lot of that from the patients. This place is supposed to have a therapeutic milieu."* *(administrator)*

At one level, staff felt that if the patient took the advice of the advocate, for example, it meant that the patient essentially trusted the advocate more than the psychiatrist. Some staff did not think the advice of the advocate should even be considered around treatment issues.

> *"Treatments can be changed and questioned - but within professions, by other medical people, not by a lawyer... they should stay out of treatment stuff, it's not their jurisdiction"*
> *(nurse)*

Loss of authority. In the staff's mind, an important part of their therapeutic relationship was the sense of authority they had on their wards and with individual patients. It was as if authority was synonymous with respect, (an important ingredient in the therapeutic relationship). Encouraging people to exercise their rights seems to encourage them to question that authority.

> *"Nurses have a clear role. They must keep things under control. The advocate upsets this."* *(psychiatrist)*

> *"You lose control over your ward, and lose authority in your position."*
> *(nurse)*

> *"Staff are laying more assault charges now. It relates to patients being less controlled by drugs and staff generally feeling vulnerable and less in control than previously."*
>
> *(nurse)*

Patients did not believe that staff have less authority and control. In fact, about half the patients mentioned that they would like to see the hospital wards changed so that the atmosphere was 'less controlling'.

> *"Staff should see patients as human beings, as equals. We may be at different functioning levels but we're still all human beings. They make it clear that they have the keys and we're the patients."*

> *"Nurses should be less in awe of the doctors and their prescriptions. They should consider our views and the team - ask the OT, psychologist, social worker - and ask how they've done things to get a broader picture."*

A small number of staff saw this issue of authority in a similar way to patients.

> *"If a patient refuses medication, that's his right. You mark it in your ward book and that's basically the end of it...unless in the extreme case, where the patient is self-abusive or something."* *(nurse)*

> *"The advocacy program expedited the improvement in rights from a master and slave relationship to more of a client relationship. It keeps everybody on their toes and brings out better potential of the staff."* *(nurse)*

Not All Negative

Not everyone perceived this issue in negative terms or felt there was a problem. Several staff, including some psychiatrists, simply did not feel as negative about the issue of rights interfering with treatment as did the majority of staff.

> *"The conflict between the doctor's orders and the patient's wishes is not a major problem. It is part of our work to carry on negotiations between the staff, patient, and doctor. We are here to help the patients. Sometimes a doctor gets hooked on one kind of medication and if we know it's not appropriate, we will call the advocate to assist - the advocate has more legitimacy and weight with doctors than we do."* *(ward supervisor)*

The only group that clearly indicated that the PPAO has had a positive impact on treatment were the advocates. Advocates at 5 sites indicated that their presence had led to improvements in the treatment procedures at their hospitals. For example, patients had more involvement in the decision-making process and treatment was more consultative and based on informed consent.

> *"The quality of medical and psychiatric care has improved because the advocates have been the people pointing out the low quality of care; the administration is now trying to hire more competent psychiatrists."* *(advocate)*

A Context to Rights Versus Treatment

It is very difficult to attribute the impacts discussed above to the PPAO. Although a significant minority of staff perceived that patients' refusal of treatment had been caused directly by the actions of the advocate, we simply don't know if this is the case. Furthermore, hospital data and PPAO data showed that only 3 per cent of all PPAO cases deal with medication and that only a small number of cases taken to the RRB are related to treatment refusal. A comprehensive review of research (Appelbaum and Hoge, 1986) found that, while a substantial percentage of psychiatric patients will refuse treatment with medication at some point in their hospitalization, fewer of them (averaging about 10%, but ranging from 1% to 15%) will do so consistently and in a manner that leads to a procedural review. Ontario data seemed to confirm this finding that "the feared epidemics of clinically significant treatment refusal, therefore, have not materialized to date" (Applebaum and Hoge, 1986, p. 281).

Nevertheless, staff perceptions that the PPAO had a negative impact on clinical interventions were supported by other medical people involved with patient advocate programs. The main issue they seemed to focus on was that patient advocates have "power" without clinical responsibility and that major problems resulted when "power" was wielded by people who lacked an appreciation of the clinical complexities. Lamb (1981) felt patients' rights should not be treated as if they were a sacred cow, but instead the difference between 'responsible' and 'irresponsible' advocacy should be established.

On the other hand, Book (1987) noted that psychiatrists often react to drug refusal with ineffective approaches such as exhortation, or rejecting the patients' concerns. The concern of patients in this evaluation that they want more time to talk with staff may support Book's contention that psychiatrists need to "work through" with patients their concerns about taking drugs or not taking drugs. Applebaum and Roth (1983) also presented data that physicians do not do a very good job in responding to patients who refuse.

Staff and advocates had very different views of the impact of the PPAO on the 'best interest' approach generally practised by staff. The literature, however, is beginning to document research which substantiates some of the advocates' and patients' concerns about failure of the system to look beyond the traditional medical model for solutions. In an interesting research study by a psychiatrist, it was determined that 'refusers' of treatment may "retain a healthy skepticism about doctors, medicine, and psychiatry and some sense of themselves as not without power and control over their lives. These qualities may have helped the 'refusers' to better cope with life outside the hospital" (Hassenfeld and Grumet, 1984, p. 72). Appelbaum and Hoge (1986) had similar findings from a review of the literature and concluded that while 'refusers' may initially do more poorly, if ultimately treated, they do at least as well as other patients.

It is important to try to understand the 'rights versus treatment' debate within the context of broader models of advocacy and mental health. Eth et al. (1984), in their article on the ethical conflicts between advocates and psychiatrists, suggested a compromise position between the two competing models which operate and make it difficult to appreciate each other's viewpoint. The first model is the patient autonomy model where the advocate's sole loyalty is to the client and assisting the client in achieving his or her wishes. The second model is medical paternalism in which clinicians and advocates should do what is in the best interest of the patient as determined by the clinician. And the third, or compromise model, is the ethical advocacy/role integrity model where advocates and clinicians should be faithful to their role, candid to others as to the nature of their role, respectful of others' roles, and obedient to the law. This analysis suggests that the conflict between "rights and treatment" can be reduced by the recognition and acceptance that staff and advocate roles differ.

Our respondents' perceptions in fact represented these various models. For example, a small minority of staff we interviewed were so negative about their perception that rights interfered with treatment that it clearly implied that these staff attach no value to the patient participating in his/her own treatment. Furthermore, the adamant denial that patients might benefit from expressing their rights reinforced that treatment in fact should be based on coercion.

As we have noted, this minority view has been well represented in the literature, as has the opposite "rights" perspective. Rather than continuing to dichotomize rights and treatment, however, some of our data emphasized the possibility that negative impacts could be minimized in this area by a more concerted effort to integrate rights and treatment.

In relating this analysis to our earlier discussion, Schafer (1985) contrasted the paternalistic and the civil libertarian view of non-consensual treatment and says competent patients' right to refuse must be accepted, even if it seems foolish; and that before the decision to treat without consent is made, every possible consideration needs to be given. The person who has been judged temporarily incompetent to care for him or herself outside of the hospital, may still be able to make treatment decisions. And finally, the more invasive, prolonged and controversial the treatment, the greater the burden of proof needs to rest on those who wish to impose non-consensual treatment.

How to Minimize the Rights/Treatment Conflict?

Staff Education. Advocates felt that the best way to bring treatment and rights closer together was through staff education. There needs to be an attitudinal change so that staff see themselves as a resource for patients in the area of rights. Staff need to understand rights as an integral part of treatment.

> *"Staff need help seeing therapy as a process with rights as an integral part of therapy. The goal is for patients to set their own goals and you facilitate them reaching their goals. In this way, patients internalize concepts and can cope when faced with choices in the community."*
>
> *(advocate)*

> *"Staff need to see themselves as someone available to patients to offer advice and resources; but now staff are controlling. They provoke the patient into acting aggressively and then can justify their needle. Staff need to see the person is just asserting their right. Both staff and patients need educating. "* *(advocate)*

> *"It would take a lot of listening by teams to the experiences of people to narrow the we/they gulf and to appreciate not only the effects of medication but the effects of hospitalization on the person."* *(advocate)*

Our data from patients and a small minority of staff, mentioned earlier, have supported the view that reduction of staff paternalism would decrease the conflict concerning 'rights versus treatment.' Others have pointed out that advocate education may be just as important, particularly if it could teach advocates to do 'responsible' advocacy (Lamb, 1981).

Involve the Patient in Decision-Making and Planning. Again it was advocates who felt most strongly that patients' involvement in decisions about themselves and the hospital can alter the rights/treatment dynamics in a positive way. Several psychiatrists also raised the issue. Perhaps this is because physicians, at least in generic settings, have had relationships with patients where the patients are more involved, so they can see it realistically as a goal for the person.

> *"Both the legislation and the advocate office probably accentuate the differences between rights and treatment, but when the patient is part of the treatment, then the tension is reduced."* *(advocate)*

> *"Since the patient is seldom part of the treatment team, it would be interesting to find a ward or setting where the patient was on the team, and in fact, was the center of the treatment team. I suspect that the patient's presence in a respectful planning mode would integrate in a most careful way the treatment and rights issues."* *(psychiatrist)*

> *"The advocate is perceived as standing in the way of treatment but actually the advocate is not standing in the way but trying to influence how the treatment is given i.e. patient involvement in the treatment and decision-making, removing the passivity."* *(rights advisor)*

Recently, a great deal has been written about specific ways to involve people who have directly experienced the mental health system in planning and decision-making (Anthony et. al., 1982; Hutchison et al., 1985). In another publication, Walker (1985), acknowledged that there were times when the wishes of the client appeared to conflict with treatment goals, but when faced with this dilemma, treatment worked best when the client and treatment team work together as partners. "When the client participates in treatment through free and informed consent - in other words when they own their treatment - the results are more likely to be positive" (p. 7). There are similar findings on coercion about admission procedures (Shannon, 1976); rights being explained and the availability of an ombudsman (Toews et al., 1984); and opportunities to explain personal feelings about reactions to certain drugs' effectiveness and side effects (Carpenter, et. al., 1977; Van Putten, 1978).

A few staff mentioned that not only should patients be involved in planning, but nurses should be present when rights are being explained, to ease their anxiety about whether the person is being told both sides.

> *"Nurses should be there when their rights are being explained. This would make staff and the advocate seem like they are working together."* *(nurse)*

Use Least Restrictive Environment. A part of the tension between advocates and staff was the belief that people with mental health problems could be provided with support services and rehabilitation in a less restrictive environment than the hospitals. It is for this reason that advocates appeared supportive of earlier discharges and focused on good discharge planning that would incorporate proper community supports. This thrust towards using the least restrictive environment is not new. Mental health advocacy in the U.S. has emphasized that "persons deprived of liberty for the sake of treatment must be treated in the least restrictive setting" (Wald and Friedman, 1978, p. 140).

> *"Treatment should be in the least restrictive environment and in chronic cases, physicians should be willing to take more risks. They wouldn't be sued if they carefully documented their reasons for choosing a certain course of action."*
> *(psychiatrist)*

Another important analysis in the literature suggested that we are moving beyond the first generation of legal advocacy which focussed on the issues of deprivation of individual liberty, compulsory treatment, and the right to treatment. The author noted that in the second generation, the main concern will need to be the effort to take "the difficult steps toward creating a decent system of mental health care." (Rubenstein, 1986, p.1266). He emphasized there will need to be joint efforts of lawyers and psychiatrists to expand housing and other services in the public sector necessary to meet the needs of patients, and he noted some examples of such co-operative efforts of using the law to obtain community services and income support.

How to proceed towards a less restrictive model is the current challenge.

> *"If we are going to give up the old model, that' s fine, but we need the new model in place, with all the supports it requires; but now we are stuck somewhere in between and if we don't do what has to be done to fully implement model 2, the community will overreact and force us to go all the way back to the old model --then everyone will have lost."*
> *(psychiatrist)*

Anthony et al. (1982), who have done extensive research on psychiatric rehabilitation treatment programs, have identified ten essential ingredients for the development of such programs. Client participation and community involvement have been found to be central to the services of the rehabilitation process.

Summary

A strong minority of staff felt that the way rights were being presented to patients, interfered with treatment. Staff felt patients were making inappropriate decisions about not taking their medication. And even worse, that the advocate was encouraging a negative rapport between doctors and their patients, thereby affecting the treatment process. Patients did not perceive a conflict between rights and treatment.

Some people were enthusiastic about ways to try to decrease the rights/treatment gap. Suggestions around staff education and patient involvement in decision-making and planning were given. Combined with the development of a more responsive, community-oriented mental health system, these ideas are receiving increased attention in the literature.

D. IMPACT ON HOSPITAL DYNAMICS

There seemed to be a fair degree of agreement among the four major staff groups that the Advocate Office has had a relatively negative impact on overall hospital dynamics. There were three major negative areas that people's feedback fell into: hostility, fear, and concern for legal protection. On the other hand, at a small number of sites, each staff group also noted that the change in atmosphere was probably due to causes other than the PPAO. Finally, a small but significant number of staff reported that the program is now more accepted and has had a positive impact. A summary of the various impacts on hospital dynamics is presented in Table 14.

Negative Impact

Hostility

Several terms were used by people to describe their hostile feelings towards the PPAO including: anti-psychiatry and anti-therapeutic, tension, resentment, destructive, anxiety, insulted, interference, adversarial, polarization, and stress.

The majority of people in all four professional groups (psychiatrists, nurses, social workers, and administrators) concurred about the hostility created by the program. However, the four sites which had reported having less adversarial advocates also reported having less hostility. As well, two other sites reported relatively less hostility.

Table 14

Positive and Negative Impacts of the PPAO on Hospital Dynamics

Positive	Negative
good co-operation	hostility
a little tension a good thing	fear leading to caution and indifference
initial tension soon overcome	concern for legal protection
	advocates as scapegoat

Nurses and social workers generally felt that the advocates have the most hostile relationship with psychiatrists and this seemed to affect everyone else.

> *"The animosity between psychiatrists and advocates spills over to other staff. "* *(social worker)*

The staff gave lots of specific examples of interactions with the advocates which they felt were interfering and adversarial. Similar complaints of advocates in other movements appear in the literature (Lamb, 1981).

> *"The advocates have sometimes taken destructive steps like threatening staff with lawsuits, writing to professional licensing bodies, and going to the media with erroneous information...It is tremendously destructive...Not too many would say the atmosphere has improved in this hospital...The assumption is that we are against these patients and so therefore the other group is in place to protect. That's unfortunate."* *(psychiatrist)*

> *"The advocate came on the geriatric ward and went through pointing to various patients saying 'sheet support, sheet support, sheet support.' [The advocate] didn't come and speak to staff and ask what our procedure is - we have doctors' orders."* *(nurse)*

A few rights advisors and advocates agreed that they appeared to be interfering and producing conflict by their activities.

> *"The staff say 'what are you trying to do? Disturb our program? The advocate is intrusive."* *(rights advisor)*

> *"Selected ward initiatives of the PPAO have introduced conflict into these settings. For example, the mental retardation ward feels threatened because questions have been raised about people and restraints; and the guidelines and new legislation are challenging the restraints, and they feel that the PPAO is strongly supporting these stands."* *(advocate)*

With this kind of atmosphere, staff felt it was difficult to get good staff to work at the hospitals, particularly psychiatrists who were already in short supply.

> *"Its hard enough recruiting MDs in this system. When you're under attack, it will be impossible...We feel under attack. We are accused... We are employees and follow the Mental Health Act. The hospital is really under attack, not us. But the hospital didn't support us. We had to fight to get them to get lawyers for us."* *(psychiatrist)*

> *"It's very hard to get psychiatrists here and the advocate program is seen as just one more negative working condition. If we can't get psychiatrists, that's O.K. by me, but we better change the legislation because it makes our system reliant on psychiatrists."* *(administrator)*

Hoaken (1986) agrees with this last quotation and goes on to say that if we cannot trust psychiatrists to make treatment decisions, the court should make them.

With this kind of hostility and tension in the hospitals, most administrators and several medical directors felt they had to play an important mediating role.

> *"She is not troublesome for me, but she is for medical staff. I have to smooth over the water. As director I can only push the staff, especially the doctors, so far. I am in favor of the PPAO; it's consistent with my philosophy."* *(administrator)*

> *" I try to be a lubricant or it would have seized up long ago. It is a lot more comfortable to try to deal with conflict; I try to see the hospital goals and try to incorporate the advocate into these goals; but the advocate fails to see the overall goals. Compromises are made all the time. Do you think we don't have idealistic nurses and doctors too? They could all be in total conflict all the time.When the*

> *advocate came, she was told to anticipate difficulties from psychiatrists; it has been a self-fulfilling prophesy."*
>
> *(medical director)*

Fear Leading to Caution and Indifference Amongst Professionals

All four professional groups had feelings of fear, although some expressed it more strongly than others: nurses (8 sites); administrators (7 sites); social workers (5 sites); and psychiatrists (4 sites). This finding made sense perhaps, since nurses had to work most closely with patients and therefore were more exposed to scrutiny. They also perceived that they had relatively little power and felt as if they could be blamed easily. Psychiatrists, on the other hand, probably have more confidence in their power and therefore have less fear; at the same time, however, they may feel threatened because of what they have to lose.

Several of the words and phrases used to express this issue included: fear, hanging together, indifference, threatened, vulnerable, paranoia, harass staff, policing, caution and intimidation.

A minority of staff felt that their fear immobilizes them from performing even some of the basic things they used to do, sometimes to the point where they become indifferent.

> *"There is a fear amongst professionals and many are becoming indifferent. If they believe they will suffer repercussions for treating, they may decide not to bother.I know of some doctors who work at avoiding the Review Board by giving in. They feel inadequate regarding the legal system and some don't want to have their decision overturned in front of the patient. Also it is a hassle."*
>
> *(psychiatrist)*

> *"Sometimes it takes us 4 or 5 staff to get a person in seclusion. The advocate comes and wants to see the person. The RN is responsible and doesn't want to open the door. The advocate insists. So the RNs feeling is 'OK - you open the door and let's let happen what will.' "* *(nurse)*

Many staff felt as if they were being policed by the advocacy program and have become cautious. Most advocates also noticed this caution.

> *"I'm not a jailor. The program insults me. It says I'm bad. It's a program set up to protect patients from staff by the same people that hire us to treat patients!"* *(social worker)*

> *"They see me as an inspector. They defend themselves to me - 'I'm doing this lock up because... is that all right with you?' "* *(rights advisor)*

> *"Staff view this program as policemen reporting them to the administration. They close ranks when they feel threatened; I suppose there is some value to the advocacy program if closing ranks helps the patient i.e., if staff are angry with the patient, then divert it to the advocate instead. But the advocate has a no-win situation if she's going to do her job, unless she is very smooth and diplomatic."* *(administrator)*

> *"Staff are more careful and cautious in using their arbitrary discretion e.g., control of finances for discipline."* *(advocate)*

Finally, staff, especially nurses, felt threatened and defensive about the prospect of criticism.

> *"Staff are very concerned about being criticized or subject to scrutiny by the advocate in their day-to-day working on the ward."* *(nurse)*

> *"Instead of trying to be helpful, we are becoming more defensive. It seems like you are on the block all the time."* *(nurse)*

Concern for own legal protection

Closely related to staff's fears regarding criticism was the concern of a minority of staff for their own legal protection. Again, nurses were the most concerned.

> *"There is greater caution in areas where rights might be an issue, in other words, CYA (cover your ass) and be ready for the enquiry."* *(advocate)*

> *"Staff are afraid to act within the Mental Health Act such as restraining patients for the protection of themselves or others, either manually or chemically."* *(nurse)*

Several staff members made the point that they needed someone to protect them, just as the patients now have.

> *"The College of Nurses is there to protect the public from us. Nurses are held responsible if the patient who refuses*

> *meds injures someone - the nurse can be sued. But there's no one to defend us."* (nurse)

> *"There were 400 assaults of staff in this hospital in a one year period. Staff need protection. What about an advocate for staff? There are issues - legal and clinical."*
> (social worker)

Advocates as Scapegoat

A small minority of people in each site suggested that the advocate was really a scapegoat and that the changed dynamics in the hospitals were probably not just the result of the advocacy program, but instead related to broader trends.

> *"The advocacy program has created a polarization; we already have a union which goes to extremes, we don't need front line staff also doing this.The fact that there was no consultation, combined with the fact that Bill 7 came down overnight, created a backlash and where else do you think it would go except towards the advocate? But the advocates are police for the legislation. But policing and advocacy roles are not consistent."* (psychiatrist)

> *"The legislation contributes to changes in the atmosphere, it feels very adversarial... the Mental Health Act is to blame but the advocates get the brunt of the anger."*
> (nurse)

> *"The positive thing is that staff have an identifiable scapegoat; they can direct some frustrations at us."*
> (advocate)

> *"In an ironic way, the PPAO has given a kicking boy to the administration and the union...In another way we have to be wary of being used by one group for their ends. There has been an increase in tension because there have been a lot of changes. But the staff blame us for a lot of the changes. They give us more credit than we are due."*
> (advocate)

Several people, particularly administrators and medical directors, were very skeptical about the intent of the government in establishing the advocacy program. Applebaum (1986) reflected similar concerns: "The improvement of conditions in mental facilities...is highly dependent on the availability of adequate funding...this funding is almost nowhere in evidence. One has the sense that advocacy is being embraced as a substitute for adequate funding, an approach that is doomed to failure" (p.9).

> *"It's not just the advocate who is the problem; it is the Review Board and the legislation, the whole attitude of anti-psychiatry. From a political point of view, it was easier for the Minister in responding to lobby groups to give money to a patient advocate program instead of putting money into programs and staff."* *(administrator)*

This latter criticism, which implies government has ignored its responsibility to improve the minimum standard of care, has been discussed in the literature for quite some time. Patient advocates are increasingly using the courts to force legislatures to reallocate their fiscal resources. In the United States, the courts have become "power brokers invading the formerly political territory of state governors and legislatures and deciding how state resources will be allocated within the mental health system" (Wald and Friedman, 1978, p. 141). They say legislatures are upset with the high cost of implementing minimum standards and also with courts' difficulty in balancing the needs of mental patients with other equally important demands on state revenues. Vrooman (1980) also raised this issue and further stated that the problem with the courts deciding social policy is their difficulty in assuring long term compliance with their judgments. Thus, changes have not always followed at the service delivery level.

Positive Impacts

A few people in each site were positive about the impact of the advocacy office, expressing no reservations. Sometimes these were people in administrative roles who didn't work directly with patients; other times it appeared to be a person who really understood advocacy and its safeguards; and other times, it seemed to be a person who was open, flexible, and secure in his or her role. An interesting study done on psychiatric staff inside and outside of hospitals showed that those who were most positive about the advocacy program tended to be those outside of the hospital. Case managers, for example, were less affected by the advocate and did not perceive the program to be interfering with their clinical judgements. The opposite held true for many of the staff inside the hospital setting (Bradley and Murphy, 1980).

> *"She sometimes arouses medical and nursing staff, but I don't care. I listen; I don't act. The patients should have service. If our staff can't do it, I'll let anyone do it."*
> *(administrator)*

> *"I have no real problem with the advocate. Some see her as a nuisance, but I don't."* *(psychiatrist)*

> *"It makes my job easier - to advocate. If it doesn't work, I have another means."* *(social worker)*

Many advocates felt there was good staff co-operation. It seemed that at two of the sites in particular, both the staff and advocates felt fairly positive about the impact the PPAO has had on the hospital. Again, these were sites where advocates were perceived as being less adversarial (see Chapter III).

> *"There is not a lot of tension. With the various teaching things I do, I am seen as a resource, not the enemy."* *(advocate)*

> *"Here there's been a revolution. I played a significant role in that process. It's been positive for staff as well as patients. It has made nurses more important as caregivers and not policemen. They can use a carrot now instead of a stick."* *(advocate)*

Initial Resistance to PPAO Overcome

While only a few people were categorically positive, staff in several sites (4) made it clear that initially there were problems, but now the program is much more accepted.

> *"When the advocate first came people were threatened; she was seen as the enemy. We thought patients would be going there all the time, but it just hasn't happened."* *(nurse)*

> *"At first we were threatened, but now it is an accepted program. The atmosphere on our ward is great toward the advocate; I find myself often agreeing with him."* *(social worker)*

> *"The fear has dissipated. There's a small old guard core of PNAs who still see her as a threat. I'm glad they fear her."* *(administrator)*

Summary

The most positive impact of the PPAO on hospital dynamics was that several people were optimistic that the initial tension and resentment experienced by professionals was gradually dissipating.

On the negative side, there were still many strong expressions from staff of hostility toward the PPAO, caution in their jobs, and concern for their legal protection. Overall, staff felt that these negative consequences of the PPAO and recent legislation had heightened tension in the hospitals. Hospital dynamics were less affected in a negative manner in those hospitals that had advocates who were perceived as being less adversarial.

E. IMPACT ON HOSPITAL POLICIES

There have been many policy changes at the hospitals, some of which were discussed at greater length under systemic issues in Chapter IV. In this section, we will discuss the nature of policies which have been developed or changed, people's reactions to these changes, and the role of advocates in policy development. See Table 15 below for details.

Table 15

Positive and Negative Impacts of the PPAO on Hospital Policies

Positive	Negative
• nurses and social workers acknowledge many policy changes	• psychiatrists and administrators acknowledge few changes
• advocate seen as resource for policy development	• policy development a non-issue for patients and families

Policy Changes as a Result of the PPAO

In each of the hospitals, there have been policy changes, completed or in progress, in which the advocate has had some involvement.

Psychiatrists and administrators acknowledge fewer policy changes. The psychiatrists and administrators mentioned far fewer policy changes (7 from each group) as compared with nurses (20) and social workers (11). Particularly when the content of the policies was reviewed, it was evident that psychiatrists and administrators were much more aware of the larger policy issues in which they had some involvement, such as restraints, seclusion, pajamas, fresh air, and assault policies. When they mentioned the advocate's role as a catalyst in these changes, sometimes they spoke positively and other times ambivalently.

> *"She's done some good work in helping us get rid of outdated practices like privileges and how they are administered, especially in forensic; she was a big help in getting all our wards open, as well as doors open, shower use improved, and patient privacy."* *(administrator)*

> *"Restraint policies have changed. We now have to write a very clear set of guidelines and standards. If restraints are ordered, the patient must be examined in a certain period of time after the restraints are applied. There were policies before but they've been tightened and are more explicit, more rigid."* *(medical director)*

A few of the staff were specific in stating that they felt the PPAO had made *no* or few significant impacts on policy development; psychiatrists (6 sites), nurses (3 sites) and social workers (1 site). The generalized negative feelings that some staff had for the advocacy program may have been related to their inability to recognize what work had been done by the office.

Nurses and social workers see a lot of change. Nurses and social workers, on the other hand, mentioned a whole range of more specific ward policies of which they were aware because of their more intensive involvement with patients. For example, comfort allowance, locking of bedroom doors during the day, television, training wage, and medication line-up were listed. Similar to the psychiatrists and administrators, some of their comments were positive and others ambivalent.

> *"For example, on the token economy ward, programs have to be tailored around patient rights; and there is more caution in implementing psycho-educational programs; on the other hand, changes in policies re: searching people, putting them in pajamas or seclusion, are being followed more closely ."* *(nurse)*

> *"When they first came, they complained that we doled out the patients' money. The advocate came and said you can't do that. We took out the policy and showed the advocate. This policy was changed. They now have the right to misspend. This is misplaced advocacy."* *(social worker)*

There was only one policy, wearing pajamas, that all four groups mentioned. This raised a number of questions about policies. Why weren't all groups aware of policies, especially ones that seemed to be significant? Were a lot of policies unwritten? What effect did this have on patients when the different people who worked with them were not knowledgeable about policies? Could this explain some of the inconsistencies among patients and the lack of adherence to policies, as well as legislation? And did people really understand the meaning of a policy?

It is also interesting to try to determine whether there were any differences in the numbers of policy changes across hospitals. An initial count indicated there may be some. This count was based upon people's recollection of the changes, not actual changes: Kingston (7), Queen St. (5), Whitby (5), London (4), St. Thomas (3), Brockville (3), Oak Ridge (3), Thunder Bay (2), North Bay (1), and Regional and Hamilton (0).

Some CABs Quite Involved. Three CABs identified the PPAO as having initiated and effected policy changes at the hospital level. Two of these CABs were quite involved with the patient advocate; in one case the advocate had sat on a CAB committee which developed a new policy position for the hospital.

Policies Not an Issue for Patients and Families. Finally, policy changes were almost a non-issue for patients and families. In only two sites did patients mention anything.

> *"They are more lenient in giving me my clothes now (after probing about the change in pyjama policy)."* *(client)*
>
> *"More policies are in place, but they are minimal."* *(client)*

Resource for Policy Development

Some professionals, mainly nurses and administrators, spoke in a positive way of the advocate's role as a resource for policy development. This was consistent with our earlier finding, that the most positive impact the PPAO has had on staff was in the area of being a resource for staff. It also followed that staff would feel less threatened by the advocate working on policies, rather than on specific advocacy directed at individual staff.

> *"They call in the advocate before setting up policies and treatment to work out difficulties."* *(nurse)*

> *"I asked her to chair the Fresh Air Committee, which is a very positive example of systemic advocacy and of her involvement."* *(administrator)*

> *"The advocate is on committees dealing with mechanical constraint policies and with patient/patient and patient/staff assaults. They have something to offer on these issues."* *(administrator)*

Summary

Nurses and social workers were more aware of and interested in talking about policy changes. Psychiatrists and administrators were not as aware of or as positive about the changes, perhaps because they were more distant from the day-to-day issues or perhaps, in the case of psychiatrists, because of their more general negativism towards the PPAO. Some CABs felt the PPAO had an impact on policy changes.

The advocates were very aware of policy issues, as discussed under systemic issues in the last chapter. Patients and families seemed to be much more interested in and knowledgeable about their own personal situations, and less aware of broader changes that were happening in the hospital and beyond.

F. COMMUNITY PERCEPTIONS

Meetings with interested and/or concerned members of the community surrounding each hospital were held in all of the sites. These meetings provided the researchers with an opportunity to assess the impact that the PPAO had on the community.

Treatment Versus Rights

The primary issue that emerged during the course of these meetings was the conflict between the medical and legal worlds; in other words, treatment versus patients' rights. Closely related to this issue was the fear, expressed by some, that patients' rights were being expanded at the expense of the rights of hospital staff and members of the patients' families.

> *"The physicians I hear talking are extremely upset about having clinical judgements judged legally."* *(community agency)*

> *"The advocate seems to expect patients to make decisions that maybe they can't make because they're sick."* *(community agency)*
>
> *"There is an expansion of patient rights but restriction of employee rights--Bill 7, some of the implications are really scary."* *(CMHA)*
>
> *"Our children go to the advocate and get their certificates lifted and are back out on the street. It's not good for peace of mind of families."* *(family member)*

Advocate Too Adversarial

A secondary issue, somewhat related to the first, also emerged in the context of these community meetings. There appeared to be a general perception that the role of the advocate is too adversarial, non-collaborative, and, therefore, not in the long-term best interests of the patient. Several remedies were suggested to deal with this issue, among them: PPAO should receive more training in the medical and social sciences, PPAO must become more aware of the services that are available to ex-psychiatric patients in the community, PPAO must expend more effort in educating community agencies with respect to their own role, and PPAO should work more closely with discharge planners.

The following quotations from staff in community agencies reflected these issues:

> *"I think one of the concerns with the advocates are their lack of knowledge of mental illness and the social service system at large, and that is where I think a lot of work needs to be done with the advocate."*
>
> *"I guess my concern is, we in the community have to deal with the consequences... a person does have rights and should be allowed to have these rights, but I think they have to be informed and practical. Who is going to deal with that situation for the next two weeks? Is the advocate going to continue to be supportive of the person in the community?"*
>
> *"When a person leaves the hospital against medical advice, they arrive on our doorstep without an address. No discharge planning has been done and this creates difficulties in trying to get them money and resources."*

Advocate Has Favourable Impact on Patients

Many former and current patients, as well as community agencies in several sites, commented favourably on the impact of the PPAO.

> *"The advocate informs the patient of his or her rights so that the person can place his or her situation in the proper perspective."* (former patient)

> *"It is an excellent resource for patients to give some information about what they want and need."* (community agency)

> *"PPAO is giving a true sense of respect to the patient, that is so frequently absent."* (community agency)

> *"The advocate helps the patient establish a better relationship with the doctors and nurses."* (former patient)

Negative Perceptions of PPAO

However, community agencies and individuals in other sites reported less positive impressions.

> *"The consensus here is that the PPAO is a trouble-maker."* (community agency)

> *"I have had trouble getting education or help from the advocate."* (public health nurse)

Summary

Generally, community perceptions were in line with the data provided by other sectors. The most prominent issues concerned the debate of 'rights versus treatment' and the neglect of staff and families' rights. Once again, in many sites, the advocate was perceived as being too adversarial and, thus, not working in the long-term best interests of patients. However, the advocate was also perceived as an important and valuable resource for patients.

The finding that the advocate's role is perceived quite positively by some and very negatively by others appears to be a prominent theme throughout this section. As indicated in the preceding sections, part of this discrepancy appears to be related to the 'style' of the particular advocate, with those who are more adversarial being perceived most negatively. However, it was not possible to determine in the context of this study how much the advocate's style is self-imposed and how much it was influenced by the particular institutional atmosphere in which he or she must operate.

RECOMMENDATIONS

In order to enhance the perceived **positive impacts** of the PPAO, the following recommendations are presented.

1. The PPAO needs to actively encourage and facilitate access for those patients who are currently underserved, including patients who are illiterate, non-English speaking, elderly, or developmentally handicapped. This is in order that a greater number of patients be afforded the sense of assurance, support, and protection now enjoyed by PPAO clients.

2. More extensive and simplified resources and outreach should be developed to inform and educate patients, staff, and the community about rights and advocacy in a comprehensive and systematic way.

3. The PPAO needs to develop a clear outline of ways that advocates can be promoted as a resource to staff in the area of patients' rights and that the PPAO's image as a resource should be developed by:

    - publicizing their contributions and accomplishments in the area of hospital, community, and provincial policies.

    - co-operating with supportive staff to gradually build a more positive image of the advocate.

    - reciprocating and demonstrating an interest in, and respect for, the resources that staff can provide to the PPAO.

In order to minimize the perceived **negative impacts** of the PPAO, the following recommendations are presented. Most of these recommendations are also designed to integrate rights and treatment.

4. The Ministry should develop strategies and mechanisms to encourage respect for the rights of patients and promote patient autonomy, self-advocacy, and participation in treatment decisions.

5. The Ministry should direct its hospital administrators to be responsible for assuring that there be serious consequences for staff who intimidate or discourage patients from using the Advocate Office.

6. In order to further integrate rights and treatment, to reduce the "revolving door syndrome", and to strengthen the concept of "least restrictive alternatives", the Ministry of Health should develop a plan for strengthening community living and community treatment options.

7. The PPAO should articulate its role as a facilitator to ensure patients' involvment in the planning/ treatment process.

8. The PPAO needs to develop concrete materials which clearly explain the advocacy process; this should be shared with staff to alleviate their concerns that advocates encourage people to refuse treatment or hospitalization and to ensure that advocates themselves have a process to follow which can be monitored by Head Office.

9. The PPAO should meet with union officials to jointly determine strategies for getting staff support for patients' rights and for improving the image of the PPAO among front line staff.

Chapter VI

STRUCTURE

"Mr. Speaker, the Patient Advocates will have and must be seen to have impartiality and independence. They will be there to safeguard a patient's interests, whether legal or health."

These words were spoken in December 1982 to the Ontario Legislature by the Honourable Larry Grossman, then Minister of Health. From the beginning, careful attention was paid to the question of how to structure reporting relationships with the Ministry of Health, so as to minimize the perceived lack of independence of the Patient Advocacy Program.

It was assumed that if advocates were independent of the hospitals, but placed within a reporting relationship to the Ministry of Health, they could initiate their advocacy work from "inside" the system with the full co-operation of both the Minister and Deputy Minister of Health (PPAO, 1984). Consequently, advocates reported directly to the Provincial Co-ordinator for the Psychiatric Patient Advocate Office, who in turn reported to the Ministry of Health (see Table 16). While in day-to-day practice the Provincial Co-ordinator reported to the Assistant Deputy Minister, it has been common for the Co-ordinator to report directly to the Deputy Minister or even the Minister on some issues.

As a further safeguard protecting the program's independence, the Minister created the Psychiatric Patient Advocate Office Advisory Committee. Consisting of mental health consumers and providers, as well as lay and legally trained advocates, the committee's responsibilities included:

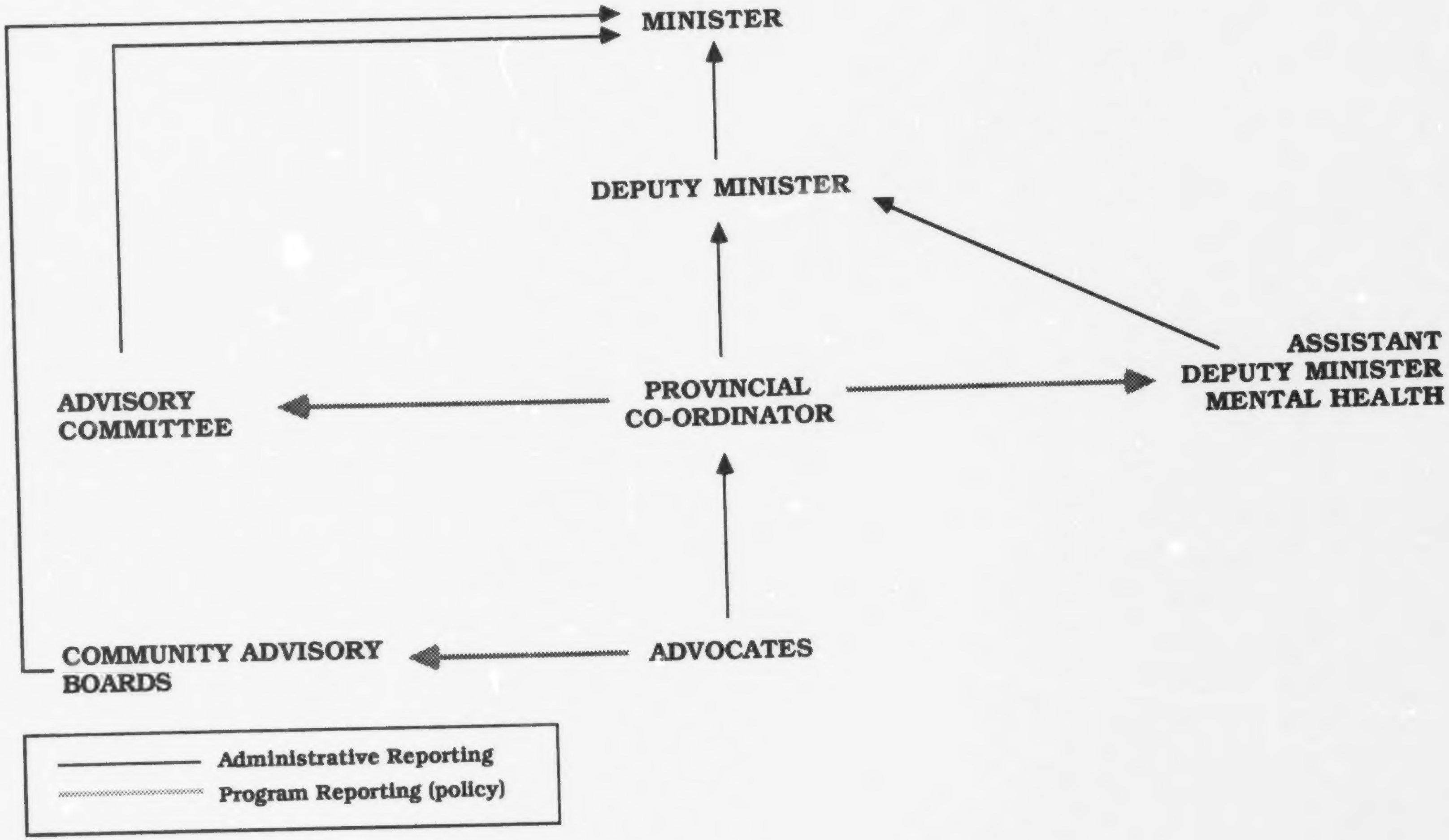
- acting as an advisory body for the Provincial Co-ordinator.

- making regular reports on the program's progress to the Minister and the Deputy Minister.

- making recommendations regarding alterations to the concept and/or design of the program.

Table 16

Reporting Relationships


MINISTER
DEPUTY MINISTER
ASSISTANT DEPUTY MINISTER MENTAL HEALTH
ADVISORY COMMITTEE
PROVINCIAL CO-ORDINATOR
COMMUNITY ADVISORY BOARDS
ADVOCATES
Administrative Reporting
Program Reporting (policy)

The question of structural independence for the PPAO has been controversial, and our findings indicated that while some people believed there are more benefits than costs to staying within the Ministry of Health, others claimed that the program's lack of independence undermined its effectiveness and credibility. In many ways our data reflected the debate about the merits of internal versus external models of advocacy. However, as Bradley (1982) discovered in her study of advocacy models, internal versus external is almost too simplistic an analysis. Rather, the issue is one of assessing the degree of dependence or independence that would be necessary for the optimal functioning of the PPAO. From a careful analysis of the data on this topic, five major issues have emerged:

- conflict of interest, both real and perceived.
- Ministry co-operation with the PPAO.
- the advocate's lack of accountability to the hospital.
- the advocate's access to information/institutions.
- the orientation of the existing model of advocacy compared to other possible models.

After examining each of these issues in detail, this Chapter will proceed to explore the alternative structural suggestions that people offered.

A. CONFLICT OF INTEREST

Our data and the review of literature indicated that the potential for conflict of interest was one of the major deterrents to housing an advocacy program within the organization that both funds the program and provides clinical services to its clients. In the literature that we examined, some of the authors were quite emphatic about the need to ensure an advocacy program's freedom from conflict of interest (Appelbaum 1986; Wilson et al., 1977; Wolfensberger, 1977). One of the authors writes that:

> Whenever advocacy is intended to be defined as constituting a social institution (in the form of advocacy agencies, citizen advocacy, ombudmanship etc.) it must be structured so as to be maximally free from conflict of interest. If it is not so structured, then the social institution that is being established should be defined as not an advocacy institution, but as some other service quality safeguard... (Wolfensberger, 1977, p.20).

Another author claimed that in the United States, the movement for establishing advocacy programs that are *independent*, is so broad based that it is supported by almost every major mental health organization including the American Psychiatric Association (Appelbaum, 1986).

Not all of the findings of this study were as black and white on this issue of conflict of interest. Respondents interviewed recognized that trade-offs exist with both internal and external models of advocacy programs.

Furthermore, a fine distinction emerged between the *functional* and the *symbolic* aspects of conflict of interest. In the former case we were dealing with real and potential obstacles that could hinder the advocates' day-to-day work, because of the program's relationship to the Ministry of Health. In the latter case, there was a concern that the PPAO's perceived lack of independence could damage its credibility in the eyes of the patients and the public. We shall briefly examine each of these dimensions as they apply to conflict of interest.

Functional Conflict of Interest

We found that advocates at seven sites believed that they had experienced some direct interference with their work as a result of Ministry intervention. Two other advocates felt that a potential conflict of interest situation existed even though they hadn't encountered it personally. This apparent interference was not always detailed by advocates; rather, advocates "assumed" that some form of discrete blocking or pressure had been applied to the PPAO.

> *"I am not aware of being told to stop an action, but there sure are some issues that have not been followed up on by the Ministry."*
>
> *"We can get our knuckles rapped for representing the PPAO at various Reviews and criticizing the Ministry."*

These rather vague feelings of unease on the part of the advocates were validated by the PPAO submission to the Review of Advocacy for Vulnerable Adults in Ontario (1987). In this submission, the following reference was made to ministerial interference:

> *"We have observed that, on the rare occasions when there has been ministerial resistance to a particular advocacy effort, it was in order to avoid the perception of criticizing another Ministry. We conclude that a branch of government whether legal, health, or social services is more likely to accept self-criticism internally than to*

> *engage in public disagreement or criticism of another branch of government."*

In our interviews with the Ministry of Health, one official confirmed that the Advocate Office had been directly interfered with on two occasions. In a third instance, the Ministry applied subtle pressure on the PPAO regarding a personnel issue. These examples demonstrated that there had been more than just a "potential" conflict of interest in the past and raised the question of how often such interference could re-occur in the future.

In addition to interference, advocates also felt that their close connection to the Ministry placed certain constraints on the work that they did. One advocate mentioned the restrictions that she imposed on herself when pursuing potentially embarrassing issues.

> *"Some issues have been embarrassing enough that an outside group might have been more effective. They could have gone to the press. "*

Half of the advocates discussed the fact that they were in a position of criticizing the Ministry without any form of job security. They expressed their feelings of vulnerability with this situation.

> *"Our jobs are in jeopardy and we have to be more careful."*

> *"The last thing they want is somebody internally putting pie on their face. They know we can go to the press, but we need protection to do this effectively."*

In their submission to the Evaluation Committee in *Whither We Go* (1986), the advocates stated that the contractual nature of their employment should be made more permanent:

> *"Permanence would strengthen our independence and enable us to forcefully represent our clients without fear of compromising our employment status."*

The advocates' concern with the program's inherent functional conflict of interest was shared by the PPAO Advisory Committee as well as by some of the community groups . People generally felt that because the advocates were paid by the Ministry against which they may need to advocate this would inevitably impair their effectiveness.

> *"This is bound to limit the incentive of the advocate to act beyond conservative bounds for fear of losing his/her job."*
> *(Concerned Friends of Ontario)*

> *"The advocates have their hands tied so they are of no real use to the inmate who is in one of the most powerless positions in the world. We feel that if they were really independent, that is if they didn't get paid by the government, didn't get paid by and didn't have to report to a Ministry like the Ministry of Health, and if they were surely allowed and fully supported to just represent the inmates instead of the psychiatrists as well, then they could live up to their name."* *(On Our Own)*

The vast majority of hospital employees (Administrators, Nurses, Psychiatrists, Social Workers), either were satisfied with the current structure or had no strong opinions one way or the other. Nursing administrators at one site said that they:

> *"want it to be in the same camp. The Ministry of Health has patient interests at heart. We would hate to see it in the legal system."*

Nurses at another hospital believed that:

> *"(the)advocate should be linked to the Ministry of Health (so they) have similar rules and regulations."*

Other staff expressed some indifference to the question of structure; it was not perceived to be an issue of great importance:

> *"I don't know if it would change anything. It wouldn't really matter where they came from if they had psychiatric training."*

> *"As long as the Ministry doesn't influence the patient advocates and the advocate is allowed to do her job properly, it doesn't matter that much."*

In the few instances where staff were concerned with conflict of interest, it was interpreted as a problem for the staff member, not the advocate. One administrator noted that:

> *"if I have a complaint about the PPAO I'm sometimes reluctant to bring it to my boss in the Ministry of Health to change the program. If it was a separate body, your criticisms would not infringe on your career."*

A nurse and a psychiatrist at two separate sites felt that it was awkward to be receiving their pay cheques from and reporting to the same boss as the advocate:

> *"(I) resent having the advocate and I paid by the same person and there is no one for me to go to if I have a complaint ."*

In a different twist on the conflict of interest question, a work study group at one psychiatric institution commented that the PPAO is not truly independent of the hospital and consequently is unable to address the major issues affecting patient care such as understaffing, lack of resources, lack of community programs and so forth.

The response from the Community Advisory Boards and the Regional Review Boards was very similar to that of the hospital staff. At one hospital, the CAB submitted a very thoughtful report on the advocate program. They acknowledged that a conflict of interest existed because of the PPAO's reporting relationship to its own Ministry. However, having reviewed the alternatives currently available, the CAB decided that the office should continue as constituted for the short term.

In the literature, various authors recommended that advocacy programs should be as administratively and financially independent as possible from the organization that also funds related clinical services. (Willetts, 1980; Wolfensberger; 1977, Bradley, 1982; Wilson et. al., 1977). These authors assume that whoever funds the program will also control the program. Bradley (1982), in her assessment of eight different advocacy models, found that many projects searched for multiple funding, "in order to maintain flexibility and resiliency in the face of shifting political circumstance." Wolfensberger's (1977) rule of thumb is that advocacy funding sources should be as many links away from the potential targets of advocacy as possible.

Symbolic Conflict of Interest

In the eyes of some of the people whom we interviewed, one of the most critical components of an advocacy program was the perception of independence. They argued that the program must be seen to be free of any conflict of interest, if it was to function optimally. A few advocates believed that the current status of the program compromised their credibility and possibly their effectiveness with patients.

> *"Many people don't take us seriously because we are paid by the Ministry."*
>
> *"Clients are suspicious of my loyalties."*

> *"When we don't win now, clients perceive it is because we are powerless in the Ministry of Health; if we were more independent, this wouldn't be a problem."*

As presented in Chapter III on Effectiveness, some clients at six sites complained of the advocates' lack of power. This was a major source of dissatisfaction for these patients. Only two people, however, linked the advocates' apparent powerlessness to the program's status within the Ministry of Health. Both of these patients were at Oak Ridge and both were very conversant with their legal rights:

> *"An advocate can't do nothing for me. I'm on my own in here and I got to stay in line...both the advocate and OPSEU (union) are Ministry of Health employees- like a body with two hands, but the advocate doesn't have a Union."*

> *"The patient advocates don't have the authority at times to do more than they can. Their hands are bound. I guess that's through not being independent of the Ministry of Health."*

In contrast, hospital staff generally didn't perceive advocates to be limited in their work because of a symbolic conflict of interest. If anything, a number of staff indicated that the advocate was *too* powerful, rather than powerless. Their primary concern was with the advocates' apparent lack of accountability. This view was also supported by **half** of the Community Advisory Boards (CAB). The issue of accountability will be discussed later in this Chapter.

Although the staff generally did not express any grave reservations about the advocate's symbolic conflict of interest, some community and consumer groups were very clear on the problems associated with the PPAO's perceived lack of independence. For example, the Advocacy Resource Centre for the Handicapped (1982) in their submission to the Honourable Larry Grossman, stated that:

> *"The lines of accountability are both confusing and provide no controls external to the Ministry of Health, leaving the ongoing appearance if not the reality of conflict of interest."*

In its submission, ARCH also pointed to the fact that the designation of the advocates as "advisory officers" under Section 5 of the Mental health Act suggested that they could be perceived by Ministry officials as an internal channel for information about the facilities. ARCH is of the opinion that staff feel threatened by this apparent dual allegiance of the advocate - to the Ministry and to the client.

Service providers' comments at the Toronto community meeting indicated that patients might be mistrustful or confused with the advocates' loyalties and the fact that advocates had offices located in the hospitals may have contributed to these misperceptions.

> *"By being housed in the psychiatric hospitals, the office is perceived by patient/clients and relatives as being among the services of the hospital and potentially part of the problem, not part of the solution ."*
>
> *(Concerned Friends of Ontario, 1987)*

> *"One of the difficulties we run into, when we asked people questions about it though, is that a lot of women perceived the Patient Advocate to be just other staff of the institution, so that when they are sometimes in confrontation with the staff of the institution, they are reluctant to involve the advocate, because they perceive that the advocate will automatically side with the staff, because they are not able to differentiate between the institutional staff and the patient advocate program."*
>
> *(community agency)*

This view of the advocate's loss of an independent identity within the institutional setting was not supported by our data from other sources. This issue was raised by psychiatrists at only two sites, and by one Regional Review Board Chair. As discussed in Chapters IV and V, some staff were concerned about role overlap with the advocate. Although it might be argued that the overlap in roles could contribute to the perception that the advocate was just another hospital employee, staff did not state that this was the case. Furthermore, in the earlier chapter on Effectiveness, the data demonstrated that patients who had used the program had few problems recognizing that the advocate was independent and, "on our side."

Nevertheless, advocates were very sensitive to the fact that the perception of their autonomy within the hospitals must be maintained. A few advocates spoke about not becoming "too cozy" with the other staff by keeping an arm's length relationship.

One of the articles that we reviewed (Eth et al., 1984) elaborated on this question of the advocate's "role integrity." The authors claimed that the advocates should inform the patients where his or her loyalty lies. If the patient is their client, advocates should be wary of playing the role of "double agents" for others within the system, and instead focus their efforts on the patient's wishes.

Summary

Although advocates were concerned that the Advocate Office's inherent conflict of interest could limit their effectiveness and undermine their legitimacy in the eyes of patients and staff, these fears were largely unsubstantiated by those most affected by the program. Generally, the question of conflict of interest was not an issue for patients and only a handful of staff stated that the program should be independent. For the majority of people we interviewed, it would seem they had not given the question of structure, or conflict of interest, much consideration.

Patients referred to their perceptions of the advocate's powerlessness, but this was not clearly linked to the structure of the program. Patients did not seem to have any problems distinguishing the advocate from staff in the hospital.

An interesting trend emerged from the submissions and interviews of those who were not directly involved with or affected by the program (i.e., community/consumer groups that provide service or advocacy to former and or current patients). With few exceptions, the voices criticizing the program's conflict of interest grew increasingly louder the further we moved away from the program, into the community. It was in this arena that the issue of symbolic or perceived independence became more controversial. Publicly, the PPAO assumed a political aura that was rarely acknowledged within the institutional settings. At only two sites did psychiatrists refer to the political pressures which they believed led to the creation of the program.

> *"The Government was under pressure from articulate minorities, who had good access to Queen's Park, and who were asking for much more intrusive changes than we could cope with and finance; so the government produced a politically presentable response to pressure."*

The fact that the staff and patients who had direct contact with the advocates' services were generally not concerned about conflict of interest suggested that the structure was adequate at present. On the one hand, this was supported by the advocates' data which showed that while the advocates suspect Ministry intervention, they were unable to substantiate their allegations with concrete examples. On the other hand, our research did unearth several cases where the Ministry directly intervened in the affairs of the Advocate Office.

It's difficult to know how much importance should be attached to the fact that in four years the Ministry of Health has asserted its authority on only a few occasions. However, just knowing that the potential for interference exists, has created a very real concern in both the minds of the advocates and the aforementioned community groups. Given all these factors, there appears to be a need to develop legislative safeguards to enhance the *perception* of the PPAO's independence and the day-to-day *functional* independence of the advocates.

B. MINISTERIAL CO-OPERATION

An interesting paradox framed our understanding of ministry co-operation as it related to the structure of the PPAO. On the one hand, the advocates' reporting relationship with the Ministry of Health had been perceived as undermining their ability to act independently. On the other hand, it was acknowledged by the PPAO that it was the very closeness of this relationship that gave the advocates their "leverage" in creating systemic and legislative change.

> *"The PPAO has experienced on numerous occasions excellent co-operation and backing for its positions from hospital administrators, the Assistant Deputy Minister of Mental Health and on occasion, directly from the Minister. We are aware that in some instances it is highly unlikely such positive results would have been obtained from "the outside."* *(PPAO, 1987)*

These views were echoed by the PPAO Advisory Committee. While the committee believed that a conflict of interest was inevitable with the current structure, they also stated that having the "teeth" of the Ministry of Health was a very positive feature of the PPAO.

> *"If the program is to become more independent, it must not lose those teeth... It must have direct capacity to pull the full weight of the Minister when necessary."*

The advocates themselves wrote that:

> Our unrestricted access to the upper echelons of the Ministry has proven to be beneficial in the pilot phase of our program and continuing access at this level is critical if we are to provide effective advocacy for our clients. (PPAO advocates, 1986).

These views were confirmed by advocates at four sites.

The PPAO's direct access to the decision-makers was recognized as an asset by several other groups as well. One administrator, four rights advisors and CMHA branches in two communities commented on the benefits of the PPAO's access to those who have the power to effect change.

Interviews with Ministry officials confirmed people's perceptions of co-operation. One of the people interviewed stated a commitment to creating positive changes within the hospitals and claimed there had never been a conflict of interest in dealing with both the advocates and the institutions. The official clearly believed the PPAO would lose some of its effectiveness if it was to move further away from the Ministry.

> *"Some of the clout would be lost if it moves outside. We must understand that the key to change in the hospitals is the Ministry negotiating with each hospital. If the reporting relationship was totally outside, what would ensure the Ministry would negotiate with hospitals and make improvements?"*

Another Ministry official talked very openly about the Ministry's support for the program to date. However, it seemed inevitable the existing co-operative relationship would suffer somewhat if the program were to become more independent.

> *"If they were outside the Ministry, the relationship would be altered and you couldn't count on my support."*

Advocates worried, however, about the permanence of this co-operative relationship, irrespective of the question of independence. If the good-will that existed between the PPAO and the Ministry was largely dependent upon the personalities involved, this placed the program in a rather vulnerable position. Four advocates wondered what the consequences would be if the Ministry personnel directly involved with the program were to change.

> *"The Ministry presence is more positive than negative, but it might fail if staff personnel at the Ministry change; so in this sense, it is very tenuous."*

> *"If there were different people in these jobs it could be disastrous."*

> *"We haven't got a leg to stand on, just sheer good will."*

In the PPAO submission to the O'Sullivan Review (1987), they raised the same concerns.

> *"It is acknowledged, however, that the PPAO relationship within the Ministry is highly dependent upon the commitment and good will of the personalities involved.*

> *Personnel changes could have disastrous rippling effects that could rapidly inhibit our ability to serve clients."*

These comments pointed to the fundamental instability of the PPAO in its current structure. The perceptions of the advocates and the PPAO clearly emphasized that the value base of the program was too closely tied to specific individuals within the Ministry.

This issue was pursued by the Advocacy Resource Centre for the Handicapped in its submission to the PPAO Evaluation Committee. ARCH discussed the Ministry's autonomy in appointing the co-ordinator of the program and claimed that the philosophical position of this person could reflect the views of the government rather than the values of the program. As a safeguard, ARCH suggested that such appointments should not be made behind closed doors.

> *"Otherwise the values of the program, reflecting as they must those of the co-ordinator, are likely to shift with the political winds."*

The Ministry recognized the validity of these concerns. One official indicated that although it would be "political suicide" for a Minister to shut down the program, there were no guarantees as to how the PPAO would be managed if the current Ministry people moved.

> *"(If we went), the way its handled would be altered. The effect would be diminished ."*

Obviously the issue of Ministerial co-operation was intertwined with the previous discussion of conflict of interest. The potential existed for the Ministry to influence not only the philosophical values of the program, but also the systemic work that is a critical part of the advocate's mandate. Willetts (1980) claimed there would always be officials who felt uncomfortably challenged by the advocate and, "even the most carefully designed advocacy programs are vulnerable to attack from threatened officials" (p. 374). In a similar vein, Wilson et al. (1977), have queried advocates' ability to resist adverse political forces.

> Advocates who engage in litigation to dismantle institutions will simultaneously be assaulting vested political interests. These hostile political factors may promote a tendency among State-supported advocacy organizations to focus upon the problems of individuals rather than to attack the malfunctioning of a system.

The PPAO claimed that although the potential for conflict with the Ministry is very real, in actuality the PPAO frequently took opposing stands to the Ministry. The advocates testified against the Ministry at Review Board Hearings and inquests, and made referrals "in order to begin litigation proceedings against the Ministry" (PPAO, 1987). Furthermore, members of the program have been publicly critical of the Ministry, the latest example being the PPAO opposition to parts of Bill 190, legislation related to a competent patient's ability to refuse treatment without an over-ride.

Summary

A unique relationship seemed to exist between the Patient Advocate Program and the Ministry of Health. The PPAO was very dependent upon the good will of the Ministry in order to implement policy or legislative change. Yet at the same time, the program must protect itself against co-optation and must feel free to openly criticize, and in some cases bring litigation proceedings against, the Ministry.

This discussion highlighted the essential paradox of the Patient Advocate Program as it is currently structured. It seemed that the potential for conflict was immense, although to date Ministerial co-operation has been readily available. However, the fact that much of the program's success appeared to depend upon the values and commitment of key Ministry officials suggested that the program required specific safeguards to ensure its ongoing functioning in a critical and effective manner.

C. ACCESS TO INFORMATION/INSTITUTIONS

People immediately involved with the Advocate Office identified access to information as an important consideration when weighing the benefits and detriments of increased independence from the Ministry of Health. The PPAO, Ministry of Health, and advocates at six sites all emphasized the advantages of the current procedures related to access to information.

Under Section 5 of the Mental Health Act, the Minister has discretionary powers to designate persons as 'advisors'. These advisors have access to the psychiatric facilities and to virtually all information pertaining to their clients. For advocates, this has included daily ward reports, incident reports, and clinical files. The PPAO pointed out that the current internal advocacy model allows comprehensive access to internal documents even in those cases where the client is legally incompetent to grant authorization.

In addition to accessing patient data, advocates at two hospitals cited other examples which illustrated the extensiveness of access under Section 5 of the Mental Health Act. In one hospital, the advocate has been granted access to all administrative policy documents that have some bearing on a patient's case. In another hospital , the advocate believed that she was entitled under Section 5 of the Mental Health Act to obtain a copy of an external review of her clients' attending physician. When the hospital administration resisted, the Ministry intervened on her behalf and the advocate was eventually allowed to read the report.

Although access to information appeared to be a positive feature of the PPAO, it should be noted that access under Section 5 of the Mental Health Act was granted at the Minister's discretion. Theoretically this privilege could be revoked by the Minister at any time.

One Ministry official noted that the PPAO and the advocates also had quick access to Ministry information through official and informal sources. Advocates appreciated this readily available channel of communcation and were reluctant to lose it.

> *"It's good to know you can access the Ministry and the informal grapevine of information is also good."*
>
> *"With systemic issues we get word quickly to and from the Ministry."*
>
> *"If we're not under the Ministry of Health, we won't get the ear of the Minister."*

The advocates were not the only ones who had something to gain from the information exchange with the government. Ministry officials acknowledged that the ability to assess feedback from the PPAO office on an ongoing basis serves as a type of corrective tool for modifying hospital policies and practices. This suggested that the current two-way communication flow is mutually beneficial. However, it also underscores the somewhat precarious balancing act that the PPAO must maintain in order to preserve its integrity.

Access to information was only one half of the equation of the current structure of the Patient Advocate Program. With their offices located within the psychiatric hospitals, advocates also had easy access to clients, staff and formal/informal information networks. It was interesting to note that by far the majority of staff believed the Patient Advocate Office should remain within the hospital. They felt it was very important for the advocate to be easily and geographically accessible to the patient.

In their submission to the O'Sullivan Review (1987), the PPAO claimed that one of the most significant problems with external advocacy programs was the:

> *"lack of access resulting in the inability to or difficulty in penetrating the target organization, institution or bureaucracy, particularly in a timely and effective fashion."*

The literature supported these claims and suggested that if the advocate was located within the hospital there was greater opportunity for:

- resolving conflicts quickly without resorting to litigation.
- regular contact with clients thus allowing more of the daily concerns to be addressed.
- developing an easy rapport with staff as opposed to the feelings of mistrust and the barriers that an external advocate could encounter.
- developing support from the administrator (Atkinson, et. al., 1985; Mowbray, et al., 1985; Willetts, 1980; Wilson et al., 1977; Ziegenfuss, 1986) .

On the other hand, an external advocate had the advantage of i) being able to access and mobilize external forces including consumer groups, ii) focusing on the issues that may have more impact, and iii) addressing violations of rights on a broader scale rather than having to constantly respond to individual cases (Coye and Clifford, 1978).

In reviewing this literature, it appeared that the current "quasi-external" PPAO model has allowed the advocates recourse to both types of activities.

Summary

Given all these factors, what are the implications for the program if it were to distance itself from the Ministry of Health? Depending upon the structural model, one of the outcomes could be a loss of access under Section 5 of the Mental Health Act. Access to facilities, clients and their documents would then have to be legislated. This access could be limited to the clients' access to files, which would vary depending upon level of competency and the physicians' discretion. Regardless of the final structure, because of the Minister's discretion with Section 5, it would seem that some legislated access to information will be important for the PPAO. While broad access can be legislated, the argument for the broad scope of access that now exists may be diminished if the PPAO moves outside the jurisdiction of the Ministry of Health.

While access to facilities and clients could be ensured through legislation, what cannot be ensured is the informal access to government officials and hospital staff. It follows that the more external the program, the less opportunity there would be for regular communication and co-operation. This in turn could increase the likelihood that more confrontational or litigious approaches would be taken by the advocate. Some of these factors will be discussed in more detail in the section on orientation of the program.

D. ACCOUNTABILITY

Our analysis of the data indicates that within the hierarchical structure of the psychiatric institution,the apparent autonomy of the advocate was a source of frustration and confusion for many of the staff. Psychiatrists in particular were quite vocal on the subject (7 sites), but at approximately half of the hospitals, nurses and administrators also had a number of comments to make. It was interesting to note that this issue of accountability kept surfacing at various points throughout the interviews even though people were never asked direct questions on the subject.

Staff talked about the advocates' "power" and the fact that they had free access to hospital information, but no responsibility to divulge their own files and documents. In some cases there was a lot of anger expressed:

> *"Someone with that much access to information and crazy patients and no accountability at all!"*

In contrast, it is important to reiterate that a minority of patients felt that the Advocate Office had too little power and no ability to enforce regulations.

Staff discussed their frustration with not knowing how to report the advocate and to whom they should be reporting:

> *"They're not under the control of anybody."*
>
> *"Who monitors the advocates? We've had good ones but..."*
>
> *"They dance and are gone. We're stuck with it. They never have to be responsible."*

Different people suggested that the advocates should report to i) the hospital administrator, ii) a professional body, iii) the CAB, and iv) a strengthened PPAO Advisory Committee. One hospital administrator felt the hospital should even have a say in who was hired as an advocate.

> *"We should be involved in the hiring. We want it to work, but we want everyone to fit into our culture. We had a bad experience before."*

Four of the CABs and a few of the staff stated that the advocate program needed clearer terms of reference and an ongoing monitoring of quality control.

> *"(They need) clearer terms of reference and accountability. Even judges are accountable."*

> *"There is little monitoring of the program and of individual advocates. There is no quality control. It's a high profile and powerful service. It can be abused by an advocate. It's highly dangerous."*

> *"(We recommend) that the Psychiatric Patient Advocate Office be required to institute a Quality Assurance Program in order to more accurately monitor and assess, on an ongoing basis, the degree to which client needs are being met."*

One hospital was unique in that every group that we interviewed (including the administrator and the CAB) wished to comment on the advocates' lack of accountability. In exploring why this was such a concern for the institution, a few pieces of the puzzle began to fall into place. The staff had also complained that the patient advocate refused to talk to them. Several of the staff commented:

> *"They have to have a responsibility to relate to the people and this organization if they want to work inside here."*

The advocate claimed that she deliberately erected barriers between herself and the staff, believing that the patients would see her as more impartial and independent.

Advocates claimed that they were accountable "first and foremost" to their clients (PPAO advocates, 1986). The PPAO itself was accountable to the Deputy Minister of Health and the advocates' formal accountability was to the Provincial Co-ordinator.

Summary

Why is accountability such a burning issue and how is it related to the overall discussion of structure? It seems that the quasi-internal (quasi-external?) structure of the PPAO is confusing both to hospital staff and to the advocates themselves.

If the model were completely internal, the advocates would report to the hospital administration. While this would naturally curtail some of the advocates' ability to tackle controversial issues, the advocacy program would be a hospital service and as such would be more likely to have the support of the administrator. A Michigan study found that a visible management commitment to the protection of patients rights is critical for the effective functioning of an internal advocacy program (Mowbray et al., 1985).

In the case of the PPAO, where the advocate is neither completely internal nor completely external, some element of confusion may be unavoidable. Furthermore, when we look at the styles of different advocates it is worth questioning if there is substantial role confusion in this quasi-internal structure. Those advocates that tend to escalate the confrontation faster, and isolate themselves from staff, may perceive themselves as external advocates. On the other hand, the advocates who tend to establish a rapport with staff and work in a more educational role must guard themselves against the perception, or the reality, of co-optation.

It is obvious that the ambiguity in the current structure creates a dilemma for advocates. In order to maintain the appearance of objectivity, some advocates may be more adversarial than necessary, thus damaging staff relationships and compliance. Those who operate in a fashion that is more congruent with internal advocacy models, may have better staff co-operation but do so at the risk of impairing their credibility with their clients. An effective role for Head Office relates to co-ordination and implementation of mechanisms to minimize the pitfalls of any particular style and to increase the real and perceived accountability of advocates.

E. ORIENTATION

In the discussion dealing with conflict of interest, the data portrayed the people who work in this institutional system as generally satisfied with, and in some cases completely indifferent to the current structure of the PPAO. However, a number of respondents noted that they would not want the program to move outside of the Ministry for fear that it would assume a more legalistic approach.

> *"If it's in the Ministry we can bring some balances to it. If it was outside it would run wild; it would be more adversarial."*

To some extent, the literature supported the notion that an external advocacy program would be more confrontational/legalistic in its approach. Two psychiatry professors have observed that the emphasis on external advocacy services implies that mental health professionals cannot be trusted to provide adequate care and so they must be supervised (Lamb, 1981; Appelbaum, 1986). We can infer from these statements that external advocacy services are likely to provoke some resentment and defensiveness on the part of psychiatrists. From our data, it was certainly apparent that even the quasi-external structure of the PPAO provoked some of the psychiatrists, because of its perceived interference with their treatment regimes (see section on Rights Versus Treatment in Chapter V).

A study of twenty-one American advocacy models found that the programs situated outside of the mental health system tended to use the courts on a routine basis, whereas programs inside the system facilitated an internal grievance mechanism procedure for patients (Willetts, 1981). The author postulated that, "service providers are not going to hire lawyers to bring court action against themselves."

Willetts' explanation of lawyers on the "outside", non-lawyers on the "inside" is perhaps too simplistic, especially in light of the current mix of staff in the PPAO. Actually, several studies defend the view that advocacy organizations should be "multiprofessional" or "staffed with a liberal mix of lawyers and non-lawyers" (Wilson et al., 1977; VanNess and Perlin, 1977). One author argues that we are entering a new era of co-operation where the gap between "medical" and "non-medical" approaches is breaking down and we are witnessing some joint efforts between lawyers and psychiatrists as they work to improve community supports for people labelled mentally ill. As discussed in chapter V, this is a challenge to achieve the same sort of co-operative effort in the treatment realm to reduce the perceived conflict between rights and treatment (Rubenstein, 1986).

Other authors have offered different explanations to account for the more adversarial nature of external models (Atkinson et al, 1985; Coye and Clifford, 1978; Ziegenfuss, 1986). They suggested that external advocacy programs have less access to the informal methods of conflict resolution that are available to the internal advocate and, therefore, they resort to more complex external strategies. One author commented that because of their limited relationships with providers, advocates tend to, "force change through confrontations" (Ziegenfuss, 1986). As a further consequence of this limited access to the institution, external advocates may also lack knowledge of day-to-day concerns, thus focusing on legal issues at the expense of therapeutic and social complaints (PPAO, 1987).

In a further analysis of the data, it is apparent that the majority of people who offered suggestions for alternative structures, cautioned specifically against a shift to the Ministry of the Attorney General for fear that this would make the program too adversarial in its orientation.

> *"Attorney General would be more controversial. Nothing is served by getting people's backs up." "* *(CAB)*
>
> *"We feel care must be taken to ensure that psychiatric advocacy is not confined to the narrowness of a legalistic approach."* *(psychiatrist)*
>
> *"I would not like to see the PPAO have a more legalistic Ministry than it has currently; going to the Attorney General would do this; we don't want to approach therapeutic issues with legal remedies; unfortunately patients often have to resort to legal solutions."*
>
> *(advocate)*

Alternatively, the Niagara District Health Council, ARCH, and Concerned Friends of Ontario Citizens in Care Facilities advised in their submissions to the Evaluation Committee that the PPAO be incorporated into a generic advocacy body that would provide a range of advocacy services to all disadvantaged people living in institutions or communities throughout Ontario. They suggested that this generic body would likely be situated under the Attorney General.

During our interviews, half of the advocates, the PPAO Head Office and the Ministry of Health expressed their reservations with this option. They were concerned that a generic advocacy organization could become:

- too large and bureaucratic
- too legalistic in focus
- too diluted by serving such a broad range of problems that the unique needs of psychiatric patients could be overlooked.

In addition to the above concerns, data from staff and advocates clearly indicated that there were other reasons for approaching the option of a generic advocacy body with caution. It will be recalled that in Chapter IV, staff claimed that mental health training should be an important background for advocates. This need is also recognized by the advocates themselves; seven advocates state that a psychiatric/therapeutic consultant at Head Office should be an essential resource for the program. In addition, a number of advocates indicated a desire for a better orientation to the hospital environment combined with ongoing training in therapeutic issues. All of these comments pointed to the need for a more specialized program, rather than a more generalized advocacy service.

Finally, Bradley & Murphy (1980) in their extensive evaluation of advocacy models, discovered that the orientation of the advocacy program closely reflects the character or the aims of the sponsoring organization. In the early stages of an advocacy program, the ties to a respected, powerful, or prestigious parent body may actually be quite beneficial. However, the authors found that as the advocacy project became more controversial, the relationship with the sponsoring organization might become strained or severed.

The Bradley & Murphy study not only adds a different perspective to the issue of orienation, it also raises some questions about the future of the PPAO. Using the authors' analysis,we might ask whether the PPAO has benefited from its early ties to the Ministry of Health, and whether it has now reached a stage where those ties should be severed. Bradley & Murphy go on to state that multiple funding sources also tend to contribute to the stability and independence of projects, although they created some discontinuity and uncertainty of ongoing funding.

One of the Ministry officials we interviewed wondered if the PPAO was evolving into a different phase. With all the rights legislation in place, he reiterated that perhaps it was time for the advocates to assume a more problem-solving role.

> *"If they recommend independence, I won't be upset...It may even be time for a new arrangement because the process will change now. The focus will be on altering the behaviour of health care ."*

Summary

It was quite apparent from our data analysis that many people associated increased independence of the PPAO with increased confrontation. They were reluctant to change the structure for fear that this would augment the legalistic tendencies of the program. The literature seemed to validate that external programs tend to be more adversarial. In addition, staff and advocates noted that the program would be enhanced if the advocates had more specialized mental health training.

The study by Bradley and Murphy (1980) generated some provocative questions about the future role of the PPAO. Is the program evolving, as we have already suggested, from a more legalistic focus to an emphasis on education and attitudinal change? If so, what are the implications for structure, and in particular, what are the implications for access? Now more than ever, the advocates may need a structure that allows them to establish relationships with staff that are built on trust and cooperation.

F. CONCLUSIONS

This chapter began by recognizing that a discussion of the merits of internal vs. external models of advocacy was too simplistic an analysis. It is more accurate to define a program in terms of its function and relationship with the body that funds the institutional system in which the advocacy program is operating. This chapter has presented the range of data we gathered from interviews, submissions, and the literature. Our analysis of this information highlights a number of key findings. These findings can assist us in developing a list of **criteria** for making decisions about the future PPAO structure. These findings and emerging criteria are listed below.

- The PPAO's close ties to the Ministry of Health have created some conflict of interest, both real and perceived. as well as a sense of insecurity on the part of advocates. Most important, patients need to perceive that advocates are working on their behalf.

  Criterion #1. *Safeguards need to be substantially increased to improve the perception of the advocates' independence and to prevent the potential for interference by the Ministry of Health.*

- The PPAO has benefitted from the cooperative, informal relationship that has existed with the Ministry of Health. However, this relationship, dependent as it is upon the values of the Ministry representatives who are directly involved with the program, is somewhat fragile.

  Criterion #2. *The program's mandate and philosophy need to be enshrined in legislation to protect it against political pressures, while at the same time, preserving communication with the Ministry of Health.*

- Access to documentation and psychiatric facilities, designated under Section 5 of the Mental Health Act, has been a crucial component of the PPAO, in that it allows opportunities for comprehensive information sharing, informal conflict resolution, and systemic change. Further, the PPAO now has formal and informal access to Ministry of Health information.

> ***Criterion#3.*** *The PPAO's access to information about patients and the hospitals needs to be maintained in the most comprehensive form possible through legislation.*

- Accountability was a predominant issue for staff. Their concern was partially explained by the confusion of having a quasi-internal (quasi-external) model of advocacy housed within a hierarchical administrative structure. Some people believed that the program should be more of an internal model, reporting directly to the hospital administration. However, the bulk of our data indicated that the advocacy program should be more independent, not less. An additional issue around accountability, was the staff's apparent lack of awareness that the advocates are accountable "first and foremost" to their clients.

> ***Criterion #4.*** *Clearer lines of authority and accountability need to be established through a body that is removed from the Ministry of Health. The program's structure and terms of reference should be clearly documented and available to hospitals. The advocate's primary responsibility to the patient should be emphasized in staff education provided by the advocate.*

- Some respondents equated a more external advocacy program with a more legalistic approach. They cautioned against the program's orientation becoming too focused on legal issues at the expense of therapeutic and social issues. As we noted, the program seems to be naturally evolving toward more staff education and attitudinal change.

> ***Criterion#5.*** *The ability to deal with social and therapeutic issues as well as legal issues needs to be maintained with an emphasis on problem-solving/educational approaches.*

- Staff and advocates generally recognized that the advocate's role within a psychiatric institution required intimate knowledge of mental health and the mental health system.

> ***Criterion #6.*** *The specialized role of the advocate needs to be recognized and developed, regardless of the structural model of advocacy .*

- Based on their experience with a coherent, flexible advocacy program, the advocates, the PPAO and the Ministry of Health cautioned against creating a large, bureaucratic structure.

> ***Criterion #7.*** *The future structure of the program should maintain its minimal bureaucracy with centralized support and a coherent program for instructed, non-instructed, and systemic advocacy.*

Many of the structural arrangements which we examined do not meet the criteria which have evolved from our data analysis. It seems obvious that being a line program of the Ministry of Health, or having advocates as employees of the hospital would move the PPAO too close to the Ministry. In a different vein, having the PPAO report to another Minister such as the Attorney General could jeopardize access to information and might make the model appear overly legalistic in nature. Setting up a separate agency along the lines of the Ombudsman's Office has appeal, but this office would necessarily report to the legislature. There are distinct advantages to having a particular Minister responsible for a program.

RECOMMENDATIONS

We are proposing a two-tiered recommendation, one for immediate attention, and the other for future consideration depending upon whether or not a proposed provincial advocacy initiative is implemented.

1. An independent PPAO board should be established, funded primarily by a grant from the Ministry of Health, and this structural arrangement should:
    - entrench the mandate of the PPAO in a provincial statute.
    - consist of a consumer controlled Board, with a majority of members representing patients or former patients. The PPAO Co-ordinator would be an ex-officio member of the Board. Board members would be appointed by Orders-in-Council after direct consultation with all

relevant consumer groups. The main commitment of all members must be to the goals of the PPAO.

- ensure that the Board sets policy and makes major budget decisions.
- make the PPAO staff accountable to the Board.
- ensure that the Co-ordinator and the Board have ongoing access to the Minister, and the Deputy Minister of Health.
- provide for a PPAO Annual Report to be tabled in the Legislature.

2. If the PPAO is incorporated into a larger province-wide advocacy structure, the structural arrangement described in the previous recommendation should be maintained.

3. Any province-wide advocacy model for vulnerable adults that is implemented should ensure that successful elements of the PPAO, as outlined in the aforementioned criteria, are incorporated into the program. Specifically that:

- the primary responsibility of the advocate be to his or her client.
- the advocates have a specialized knowledge of the particular institution or system within which they are working.
- the program have minimal bureaucracy with centralized support and a coherent program for instructed, non-instructed, and systemic advocacy.
- the agency have a visible degree of independence from the organization that funds it and from the institution where it is located.
- the orientation of the program emphasize therapeutic, legal, and social cases.
- the access to client files, staff, policies, and facilities be guaranteed through legislation and/or contractual arrangements
- the program ensure that patients know that the advocate is on their side.

Chapter VII

INTERNAL ORGANIZATION AND RESOURCES

In this chapter, we discuss the internal organization of the PPAO and program resources. To answer our research questions, we examined the patterns among advocates, and between advocates and Head Office. Since advocates work independently and are widely separated geographically, communication, decision-making processes, and the need for personal support are important issues.

Our data analysis also suggests the need for definition and refinement of basic operational procedures as the program begins to consolidate its early innovative experiences. Finally, we discuss the human and financial resource needs of the program.

A. COMMUNICATION PATTERNS WITHIN THE PPAO

In this section, we describe communication patterns and the extensive informal communication network in the program.

Formal Communication

Formal communications have been minimal in the PPAO. Advocates have been required to send monthly statistical reports of individual cases to Head Office. The nature of these reports is under review and is discussed separately. The practice of monthly anecdotal reports on local issues or concerns has recently been abandoned. Advocates claimed that these reports were time-consuming and not timely. Further, several people indicated they did not understand the purpose of the reporting.

A few advocates continue to write monthly reviews for their own purposes. One advocate noted;

> *"It gives me a chance to reflect. It forces me to take time to review what I have done and not done. Personally, I*

> *find it very useful, but I don't do it with Head Office in mind."*

Head Office sends a regular monthly mailing to all advocates, including program policy and administration updates, relevant reprints of articles, feedback on issues, etc. Each quarter, a statistical summary is sent to each advocate comparing the casework statistics for each individual hospital to a province-wide casework summary. The annual program objectives, formulated at the annual retreat, are prepared and sent to each advocate following the meeting.

Case conferences are face-to-face meetings held every six weeks. Advocates gather for these working sessions, usually two days in length, in a central location. According to our data the meetings usually serve several purposes. Each advocate and the Co-ordinator reports briefly on recent developments. Client issues, program operation, systemic issues, and program policy are discussed. Sometimes one day is devoted to special presentations for the information of advocates e.g. psychogeriatrics, Bill 7.

Given the isolation of the advocates in the field, the opportunity to come together at case conferences was seen by advocates as an essential personal and program support. However, several advocates had a number of criticisms of the case conference process:

> *"It's like a tidal wave. Overwhelming bits and pieces that don't come to anything real. We never get to the practical, tactical discussion...what to do with all this information."*
>
> *"Case conferences are frustrating. I always look forward to them and I'm always disappointed. It's not clear what's important, what our priorities are. The goals of the conference are not clear. We deal with superficial, bitty things. We have rushed discussions, but no conclusions or follow-up plans."*
>
> *"I get the impression the legal thing is most important. Therefore, the lawyers have all the power. We feel like junior members. It feels like 'the lawyers and the girls'. We should get as much respect for our knowledge of other issues."*

Sub-committees are another way in which advocates meet together. These meetings were considered by advocates to be more successful. They focused on one topic of mutual concern and they had clear goals. Sub-committees were usually initiated in order to do background research on an issue of concern to the PPAO.

An annual retreat is held each Fall. At this meeting, annual objectives are formulated and program guidelines are reviewed and/or updated.

Informal Communication

Advocates have developed extensive communication networks used for three main purposes:

- to share professional information and gain advice about issues such as law and medications
- to gain advice on strategies
- to obtain personal support

Each advocate developed a local support system for both professional advice and personal support. With the exception of Penetang and Queen Street where there are two advocates, advocates have no one "next door" with whom to share daily events or discuss their work. Advocates indicated they get support from mental health advocates and community professionals, from family, and through memberships on boards of local organizations. A minority of advocates obtained support from a few hospital staff members, usually friends of long standing.

The majority of advocates indicated that they had a good, supportive, relationship with Head Office. Head Office staff were perceived "more as colleagues than bosses." The democratic style of the program lent itself to a great number of informal telephone contacts with Head Office. Phone calls to and from Head Office encompassed legal advice, strategic problem-solving, advance warning of issues or information from sources such as the Ministry of Health, and personal support. Head Office was described by most advocates as "responsive."

The third and perhaps most important source of support was derived from having contact with each other. Advocates provided each other with professional advice, such as involving lawyers for legal matters, and strategic advice around local issues. Finally, advocates provided personal support to one another.

The Importance of Personal Support

Advocates work in hospitals in a culture of which they are not really part. Most advocates reported feeling lonely and isolated at times. They noted that no one was immediately at hand with whom to share a joke, discuss an issue, or exclaim over daily events.

At times of stress, advocates noted that phoning colleagues or Head Office was critical to personal support and the prevention of burn-out. Better still was personal contact with other advocates, usually through sub-committee meetings.

Another source of support was the rights advisor. Most advocates considered their rights advisor as a "team" member, with whom issues could be shared. Most of the rights advisors were originally secretaries to the advocates before the rights advisor program was started. Some teams have been together a long time and have worked very collaboratively. The importance of a mutually supportive relationship between the advocate and rights advisor suggests that when new staff are hired, the fellow team member should have some input into the hiring process to assure that support is maintained.

Advocates identified three ways to help maintain and improve their sense of community:

- more opportunities for informal meetings.

"(Another advocate) is a real expert in psychogeriatrics. I'm just starting into that now. If we could just get together for a day it would be wonderful."

- visits from head office.

"I was here for a year before anyone from Head Office showed up."

- specified times devoted to dealing with personal/ professional issues.

"The business of how we maintain independence in the hospital, day-to-day, concerns us all. It is very tricky. We all worry about it. But it's never on an agenda... we just have to squeeze it in, in fragments of free time."

B. DECISION-MAKING

Advocates were not clear about the decision-making processes or about responsibility for decisions made within the PPAO. They would welcome clarity. Which decisions were made by Head Office seemed to depend largely on the Provincial Co-ordinator's style. For eight months last year, there was an acting Co-ordinator and decision-making was more diffuse as everyone carried an extra load. On the other hand, the new Co-ordinator is beginning to put into place a number of programmatic initiatives which she designed in co-operation with the advocates.

Democratic decision-making has been the general approach of the PPAO. The principle of maximum input from everyone involved and a consensus approach to decision-making was affirmed by advocates and Head Office staff in our interviews. Barriers to this approach included limited opportunities to meet together, and pressing issues where time demands prohibited consultation.

> *"It's not clear when we use consensus and when the Co-ordinator decides."*
>
> *"I expect (the new Co-ordinator) will have a different style of making decisions than the previous one. We'll just have to wait and see."*
>
> *"Recently at the case conference (working on a paper)... we were all over the map. I'm not sure we had consensus, or should have or could have. We ran out of time and the Co-ordinator was left to make something out of it all."*

C. OPERATIONAL SUPPORT

The PPAO is entering a period of consolidation. Now that the program has had four years of experience and an opportunity to evaluate that experience, it is time to define and refine basic program policy and procedures. The program philosophy of keeping rules and guidelines at a minimum is commendable. As discussed in Chapter VI, the PPAO is definitely not a bureaucracy and its smallness and networking approach are two of its most solid features.

At the same time, some commonalities are essential to increase program effectiveness and as a defence of the program. Common understandings help to ameliorate confusion and unclear perceptions; assist in explaining the program to others; and provide basic standards for hiring, orientation, and performance review.

In the following section, we discuss issues which respondents identified as needing consolidation or clarification. These issues form an agenda for internal action which will make program operation clearer to both advocates and external observers.

Program Guidelines

Program guidelines within the PPAO are developed when deemed necessary. Draft guidelines are reviewed at case conferences before becoming part of the policy procedures manual. As in many organizations, most advocates said they ignored these guidelines. Some advocates obviously integrated them into their work and no longer referred to them.

Our review indicated that some program guidelines, such as confidentiality, were not understood in a uniform manner. Others, such as the hiring policy, were incomplete. The hiring policy, for example, dealt with procedures but not qualifications. It has not been updated since September, 1984. We found no guidelines on performance review criteria or other personnel issues. In reviewing and updating guidelines, it would be useful to separate guidelines dealing with external manners, such as confidentiality or release of information, and those dealing with internal procedures, such as personnel and reporting.

Annual Objectives

Each year at the annual retreat, objectives for the program are developed for the next year. We found that these were uniformly ignored and had no influence on the work of the advocates. Respondents suggested that this was because implementation strategies were not developed and Head Office had no time to give leadership on these issues.

For the process of developing annual objectives to become meaningful, sub-committees will have to work with Head Office to devise implementation strategies and put them in place. The addition of a systemic co-ordinator at Head Office should assist in this process.

Documentation and Reporting

This evaluation provided an opportunity to review the PPAO's information system. Program data are collected from:

- monthly statistical reports from each advocate and a summary of concluded issues and outcomes.
- monthly activity reports including information on pertinent meetings that advocates attended; non-instructed, systemic, or test cases; progress reports on ongoing cases; and brief anecdotal reports.

We noted earlier that there are no guidelines for file recording of individual or systemic cases. As a result, the individual files, the systemic cases, and the anecdotal reports have been documented inconsistently across the sites. Furthermore, with Head Office not requiring the statistical recording of non-instructed cases, the documentation in these cases was very sparse at the majority of sites. When discussing this with advocates, we began to wonder if some of the informal negotiations and quiet monitoring that occurred on wards was rarely recognized as an integral component of non-instructed advocacy; they are not recorded regularly.

An additional data problem that we noted earlier was the lack of clear outcome data related to the advocate's effectiveness. The term "instructions fulfilled/not fulfilled" told us very little about the process that was used by the advocate, and absolutely nothing about the final outcome for the patient. Alternatively, the original codes, "complete satisfaction/not satisfied" were more subjective and misinterpreted by almost half of the advocates.

Looming over the whole discussion of data collection was the question of quality control. In order to ensure that the PPAO's statistics and reports were meaningful, there needed to be a clear sense of why the data were being collected in the first place. This in turn raised a series of questions:

- **What does the PPAO need to know for its own internal program management?**

  How applicable is the current documentation to policy planning and decision-making?

  Does the documentation relate specifically to the program's objectives?

  What data are not being collected now that should be collected in future?

- **What does the Ministry of Health need to know? The public?**

  How will these needs change in the future, especially if the PPAO were to become more independent of the Ministry of Health?

- **What are the data needs of the advocates?**

  Are the advocates committed to the current process of data collection?

Do they feel that quarterly reports are relevant to their work?

Do they even benefit from reading the anecdotal reports and systemic cases of the advocates?

What data would they like to see collected in order to meet their informational needs?

Are there categories of data that are being collected now but are no longer relevant to the program?

All of these questions cannot be addressed with the depth that is necessary within the scope of this report. Nor would we presume to deal with the whole issue of documentation and reporting without first proposing an intensive assessment and planning process to answer some of the essential "needs" questions raised above. Nevertheless, the findings from our interviews with Head Office staff and the advocates did suggest some areas that should be pursued.

- **What does Head Office need to know for its internal management of the program?**

  It would like to focus more on:

  -self advocacy, the process and follow-up.

  -client satisfaction.

  -the advocates' follow-up case work, with both clients and staff.

  -specific systemic issues that are identified by Head Office, such as housing.

  -non-instructed casework.

  Head Office would like to encourage more formal, analytical casework, especially with systemic issues, and build this into regular meetings.

- **What are the data needs of the Advocates?**

  Advocates would like more accurate methods for recording the process, and the time spent on educating clients or providing information for self- advocacy.

Advocates would like the statistics to more accurately reflect their effectiveness. Seven advocates talked about the need for client feedback.

Advocates would like information on the final outcome of client cases.

Advocates would like to be able to access the information that is relevant to their work. For example, one advocate would like to have data available on cases that are precedent setting.

Advocates would like to address the arbitrary closing of files after 30 days. Some advocates continue to follow-up their patients for several months, writing notes in the "closed file." Technically, the file can't be re-opened because the person is no longer a client.

- **Has there been too much emphasis on quantitative reporting at the expense of qualitative reporting?**

Two advocates mentioned that the recording of statistics is time-consuming and not always meaningful.

Head Office noted that they do not want reporting to become an issue of productivity, rather than quality.

Four advocates found the anecdotal reporting to be beneficial for their own record keeping; it was a useful way to review the files, to summarize, and keep up-to-date. On the other hand, five other advocates indicated that they had little use for this method of reporting.

The quantitative reports in their current format are of limited interest to the majority of advocates.

- **Categories of data that are no longer relevant**

A few advocates wondered why personal demographics such as age and diagnosis are being collected. There was a feeling that this infringed upon patients' confidentiality.

Head Office felt there was no longer a need to collect the specific source of referral of the patient to the PPAO. More general categories such as "referred by treatment team" would probably suffice.

As mentioned earlier, advocates queried the relevance of the"outcome data" that are currently collected.

Discussion. Obviously there are some different agendas that need to be met by the PPAO's information system. Staff at Head Office are pleased with the comprehensiveness of the statistics that are collected because of the wealth of analytical detail that is available when needed. However, the system is fundamentally flawed if the advocates and rights advisors who are collecting this range of data are not committed to the process. If the advocates generally believe that the statistics which they send to Head Office have little relevance to their day-to-day work, and that their effectiveness is measured imperfectly, then what is the incentive for ensuring the quality of data that is recorded? Five advocates expressed concerns about the possible margin of error.

At this stage, the priority should be to address the advocates' concerns and for Head Office and the advocates to work co-operatively to develop a system of data collection that is mutually beneficial. If the advocates have some ownership in this process, then concerns around quality control will be diminished. The role of Head Office should be to act as the catalyst in initiating this process of re-assessment. Once the alterations are made to the information system, ongoing monitoring will be required.

This issue of documentation and reporting is complex and probably requires extended working sessions with advocates and Head Office to develop a detailed plan of action. Once "needs" have carefully been addressed, several implementation issues such as comprehensiveness of the data and how to measure items such as self-advocacy will need to be pursued.

Two brief examples of the kinds of alternatives which might be examined are outlined briefly here.

Measuring the Advocate's Effectiveness. This should relate to the program's objectives. As advocates noted, client feedback would provide one of the best measures of their effectiveness. Given the advocates' volume of case work, follow-up is probably not possible with every client. Other options might be to ask every fifth client to fill out a short evaluation card. Alternatively, Head Office could establish an Input Day four times a year at each hospital. During this day, the advocates' clients would be asked to evaluate the advocate. The evaluation would have to clearly differentiate between process and outcome. Randomly selected staff could also participate in an evaluation on that day.

Measuring Outcome Data. It is worth knowing how many clients are achieving their wishes. This information was not being collected in a systematic fashion. Objective measures could be chosen which are not a direct measure of the advocates' effectiveness, but rather an indication of the advocates' impact on the system. For example:

- the number of clients who attended their Review Board hearing.
- the number of clients whose applications were withdrawn or whose status changed just before the hearing.
- the number of advocate-initiated cases that went before the Review Board that year.
- the clients' outcomes with regards to social and therapeutic issues (e.g. restraints removed, privileges granted, permission given to see their own files).

These measures may provide some interesting data on what can be achieved within the institutional setting. For example, if outcomes rarely go in the direction of the patient's wishes, what does that tell us?

Personnel Policies

A number of personnel issues need to be resolved. The program's history and the findings of this evaluation should assist in this process.

Job Security. All PPAO personnel, including the Provincial Co-ordinator, were hired on a one year contract without provision for benefits. Ministry of Health officials agreed that advocates should have improved job security and longer contracts. How this is achieved will depend partly on how the program is structured.

Cautions against the development of complex, multi-tiered structures and against permanent tenure of jobs were raised by a minority of respondents. They argued that effective advocacy demands a level of vigilance and dedication that cannot be maintained indefinitely. Our experience suggests that after about six years, advocates will either burn-out or become complacent. Institutional advocacy should not be viewed as a lifetime career. Fresh initiatives are essential.

We agree, however, that one year contracts are inadequate.

Employee Grievance System. There have been attempts to develop an employee grievance system, but none have emerged as yet. A grievance system should be established within the new structure of the program.

Ethics. A few ethical questions are the subject of program guidelines. Our interviews with advocates indicated that ethical questions arose almost daily. The program now has enough experience to develop an ethics casebook and standards. This process would enable advocates to discuss ethical issues in detail and to have clear standards for action. It would become an important document for the training of new advocates and a useful educational tool for hospital staff and others seeking to understand how advocacy works.

Orientation of New Advocates. To date, orientation has been largely a process of learning on the job. The program has provided opportunities for new advocates to visit and work with colleagues and to attend professional development meetings as necessary. Most advocates have designed their own orientation programs to meet their self-defined needs. Several advocates noted the inadequate orientation process.

As a result of this evaluation, it would seem timely to solidify the key elements of the PPAO (see Chapter VI) and utilize them as the basis for a more comprehensive orientation process. This will be particularly important if the program expands to other settings. Other emerging programs may want to learn from the PPAO.

Role of Advisory Committee

The relationship of the program to its Advisory Committee requires clarification. A 1983 Discussion Paper on an Organizational Structure for the PPAO stated that "the coordinator reports to the Advisory Committee which in turn reports to and advises the Minister and submits an annual report to the Minister and to the public...". Most respondents did not believe that the Advisory Committee had any reporting relationship.

The Advisory Committee noted that it has no management role.

> *"The committee is therefore advisory; the Co-ordinator has no obligation to them."*

It is still unclear whether the Co-ordinator or the Advisory Committee has ultimate responsibility for the annual report of the program. The Advisory Committee itself expressed some uncertainly about its role.

> *"At first it was clear that we reported to the Minister of Health, but later we focused most of our time giving advice to the Co-ordinator."*

Advocates were also uncertain about the role of the Advisory Committee. Two advocates reported seeking independent advice from individual committee members. Several advocates commented on a recent change:

> *"I always thought the Advisory Committee was there for the Co-ordinator to use. Now I understand that we are supposed to use it too."*

If this is the case, advocates require more knowledge of the skills and qualifications of Advisory Committee members.

> *"We have had a few social events with them, but I don't even know who all the members are, let alone what they could offer me."*

D. PROGRAM RESOURCES AND NEEDS

Human Resources

At the inception of the Psychiatric Patient Advocate Office, the Head Office staff consisted of a Provincial Co-ordinator, an Executive Assistant, and a Clerk/Typist. Since the addition of Legal Counsel to the program (January 1, 1984), a part-time clerk has been employed continuously. Since September, 1984, this Clerk/Steno has worked full-time, while the original Clerk/Typist position was redefined as an administrative Clerk 4 General position.

Until January 1986, field staff of the program consisted of 11 full-time Patient Advocates and their part-time support/secretarial staff. In January, 1986, the program expanded to include ten rights advisors. The program also obtained a second patient advocate position at the Mental Health Centre in Penetanguishene. Therefore, commencing January 1986, the field staff component (excluding 3 full-time secretaries) doubled to 22.

As recommended in Chapter IV, a full time systemic and policy co-ordinator is needed in Head Office to serve as a researcher, co-ordinator, strategist, and policy analyst. This need was identified by most advocates, office staff, the Advisory Committee, and Ministry of Health officials. The uneven development of systemic advocacy and non-instructed advocacy also pointed to the need for such a person.

Several advocates also identified the need for a clinical consultant to give independent advice on treatment and medication issues. This is a particular problem in smaller communities where there are few private psychiatrists available.

> *"I can't get a second opinion in the hospital and there are too few independent psychiatrists in the community."*
>
> *(advocate)*

Consultants should be on retainer to the program or an alternative arrangement would be to have several consultants on retainer in various regions of the province.

Physical Resources

Equipment. We observed that hospital advocate offices are sparse but adequately equipped. Space and equipment for these offices were approved by the Assistant Deputy Minister of Mental Health and are provided by each hospital.

Since one of the main activities of Head Office is the production and revision of documents, briefs, and letters, a word processor would improve the efficiency of this office.

Travel. We have identified several needs that require an increase in the program's travel budget, including more frequent sub-group meetings, more visits to hospitals by the Co-ordinator, and more continuing education opportunities. A systemic co-ordinator, if approved, would need to travel to local hospitals.

Summary

This chapter has identified a number of issues related to the internal organization and resource needs of the PPAO. Because of the isolated nature of institutional advocacy work, regular communication and ongoing support are important for advocates. Head Office staff and the advocates both seemed committed to a consensus-building form of decision-making. In conjunction with the advocates, the new Co-ordinator is evolving some interesting programmatic initiatives which will likely lead to the development of clearer guidelines in a number of areas. Our data indicated that this will strengthen the internal organization. Documentation and reporting has been identified as a major area in need of renewal. Several suggestions were noted from advocates and the evaluation research team.

Finally, several new resources will be needed within the PPAO to respond to the recommendations of this evaluation and these are outlined in the following recommendations.

RECOMMENDATIONS

Support Mechanisms and Decision Making

1. The program should maintain and enhance opportunities for the advocates to develop more personal and professional support through:

    - the allocation of more funds for informal meetings between advocates on local issues, and for routine visits to each advocate and hospital by the Provincial Coordinator.
    - specific opportunities for dealing with personal and professional support issues.
    - maintenance of the case conference mechanism, redesigned by program staff so that it is a more satisfying experience.

2. The principle of maximum input from everyone involved and a consensus-building approach to decision-making should be affirmed and supported by mechanisms outlined in the evaluation report.

Human Resources

3. A full-time co-ordinator for systemic and policy issues should be added to Head Office staff as discussed in Chapter IV.

4. Clinical consultants should be on retainer to the program for advice on clinical issues.

5. A second, full-time secretarial position needs to be added to Head Office.

6. Once the structure of the program is determined, new terms of employment that address the need for longer contracts and benefits for advocates and central staff, should be developed for all PPAO personnel.

7. An expanded orientation program for new advocates needs to be designed and implemented.

8. In clarifying the new structure, the role of the Advisory Committee, if any, will need to be determined.

Operational Consolidation

9. Program guidelines should be reviewed and updated to include matters such as confidentiality and release of information.

10. Annual program objectives need to include the definition of strategies and responsibilities and the implementation of these objectives should be monitored by Head Office.

11. Guidelines for minimum standards of documentation and recording should be developed and enforced for both individual and systemic cases so that files can be followed by other program personnel and so that advocacy activities are more defensible.

12. The PPAO should continue to review its data reporting system by conducting a formal needs assessment and then updating its documentation and computer system accordingly.

13. The program needs to begin to develop an ethics casebook and standards of ethical conduct.

Equipment and Travel

14. Head Office should acquire a word processor for the efficient production and revision of documents.

15. Additional travel resources need to be allocated to the program to accommodate: more frequent sub-group meetings; more visits to the hospitals by the Co-ordinator and the new systemic coordinator; orientation and continuing education opportunities.

General

16. The PPAO should receive funding to assist in implementing the administrative recommendations of this evaluation.

CHAPTER VIII

FUTURE DIRECTIONS and EXPANSION

Respondents were eager to discuss their opinion on the future of the Advocate Office, both in the submissions that we received, and in the interviews that we conducted. However, a rather interesting dichotomy developed between the views of the community and those of staff in the hospitals. Community respondents did not find it necessary to ponder the continuation of the program. It was assumed that the program was in place and that the issues were how, when, and where the program should be expanded. In contrast to this, a significant minority of staff and CABs began their discussion of the PPAO's future by either affirming that the program was necessary and here to stay, or by querying whether the program should exist at all. In addition, administrators, CABs, and hospital staff focused their comments not on expansion but on the internal changes needed to improve the functioning of the program. Expansion was mentioned by only one administrator, three CABs, and a small minority of staff.

These findings are not surprising, perhaps, given that staff would be more likely to concentrate on the internal management and operation of the institution, whereas community service providers and former patients are concerned with the need for more community support structures. Nevertheless, the data reinforced what we all know - that the community and the institution are two separate cultures and the patient who is discharged must bridge the gap (Herman, 1985; Hutchison, et al., 1985). Some of the community groups expressed the view that the patient advocate should have better community resource training in order to assist the clients, who are discharged, with informed decision making. As we shall discuss, this raised the question of where advocacy ends and case management begins.

In this chapter, we highlight our findings related to future directions and expansion. Because the previous chapters have documented the need for several internal changes, most of this chapter will focus on the issue of expansion.

A. INTERNAL CHANGES TO THE PROGRAM

Table 17

SUGGESTIONS FOR THE FUTURE OF THE PPAO BY HOSPITAL STAFF, ADVOCATES, AND CABS

- Increased co-operation between the advocates and the staff/CAB

  "We need to restructure the mandate so that the patient advocate works with the staff. It hasn't served much purpose in its current form. The problems are serious and we need advocates, but not the way it is at the moment where there are too many inappropriate ideas."

  (administrator)

  "The medical profession and advocate program must come closer, and be less adversarial. But this does not mean becoming more a part of the treatment team. Regular meetings with the administration and medical people would help, instead of always having to arrange them."

  (advocate)

- more attention paid to psychogeriatric patients and developmentally handicapped patients

  "To really improve and have greater impact, we would need more advocates in each hospital. There would need to be greater emphasis on people who can't speak for themselves...geriatrics, mentally handicapped people who shouldn't even be here." *(advocate)*

- more advocates within the hospital
- improved accountability/quality control of the advocate and the program
- a more professional style and process
- more emphasis on education for the staff/CABs/public regarding patients' rights and advocacy
- more frequent attendance and assistance in informing the patient, at the Review Board Hearings

Hospital staff, advocates, and CABs suggested a number of changes that they believed would enhance the future functioning of the advocacy program. Many of these changes had to do with effectiveness and have already been discussed in Chapters III and IV. A summary of the findings is presented in Table 17.

One CAB and a minority of staff at five sites, felt that the program should not exist. They stated the following reasons for discontinuing the program:

- the dollars could be better used for more qualified staff, particularly psychiatrists
- other safeguards are available such as legal aid lawyers and the Ombudsman's office
- the staff are the patients' advocates

"People have responded to the rights movement and the Act is more protective now. The legal stuff can easily be done by the social workers." *(social worker)*

"As far as I'm concerned it's a redundant role, a useless function - patients can go to lawyers, plus staff are their advocates." *(social worker)*

"I don't think it's necessary because of all the other stop-gap measures that we've got to ensure that the patient is getting treated fairly and sincerely. " *(Director of Nursing)*

The majority of staff, CABs, and administrators indicated either an acceptance of the fact that the PPAO is here to stay, or an acknowledgment that the program is necessary and should continue. The program was deemed to be necessary because:

- patients are vulnerable
- there must be the perception that rights are being addressed
- there is a need for a check on the system

"It is good to have someone looking out for patient rights. Years ago no one was looking out for patients' rights - really." *(nurse)*

"I think there is a role for them and I think it's an educational role - for staff as well as patients." *(social worker)*

> *"(The patient advocates) are the link between the clinical perspective and the legal perspective...an educational role."*
> *(social worker)*

> *"I think we no longer have a choice of if we want it or not. It's here to stay. But more communication is needed between nursing and advocacy."* *(Director of Nursing)*

> *"I would keep the patient advocate program in place so it is seen that interests and rights are being addressed."*
> *(Head Psychiatrist)*

Summary

Staff comments on the future of the PPAO focused primarily on internal organizational changes. Although there was generally an acceptance of the program and an acknowledgment of its necessity, some staff queried the need for its existence. More staff education was mentioned as a recommended change; in light of the rejection of the program by some staff, this seems to be an important recommendation.

B. EXPANSION OF THE PROGRAM

In considering whether the PPAO should expand or be transferred to other settings, we utilized respondents' perceptions of these issues as part of our data. In addition, we talked with a few key informants about the characteristics of other settings mentioned by our respondents. In making judgments about expansion, our limited data required that our analysis be somewhat conceptual. In other cases, we also extrapolated what we knew about the PPAO to how the elements might apply to other settings.

Expansion to Other Psychiatric Hospitals

In addition to the ten provincial psychiatric hospitals, there are four other psychiatric hospitals in Ontario which are not operated directly by the Ministry of Health. The Clarke Institute of Psychiatry in Toronto, The Royal Ottawa Hospital, Sudbury Algoma Hospital, and Homewood Sanitarium in Guelph have independent Boards, but receive most of their funding from the Ministry of Health.

We did not ask respondents directly if they felt the PPAO should be expanded to include these other psychiatric hospitals. Nevertheless, one advocate, the PPAO, and two submissions did emphasize the need to expand the Advocate Office to these hospitals. Given the benefits to patients, it does seem logical to provide advocates in other institutions which serve psychiatric patients.

In considering the expansion question, we also looked at some of the ways these psychiatric hospitals are similar to, and/or different from, the provincial psychiatric hospitals. Expansion of any program in many ways is an issue of "transfer." In translating programs or ideas from one setting to another, it is vital that the settings be fairly similar or that the ideas be "adapted" for the new setting.

The patient population at the four psychiatric hospitals is both similar to, and different from, the patient population in the provincial psychiatric hospitals. All these hospitals have patients who are considered chronic and part of the "revolving door" syndrome. The private hospitals, however, do have a larger percentage of "acute" and voluntary patients, and a much smaller percentage of involuntary patients. In 1985-86, for example, 46 per cent of patients at the provincial hospitals were involuntary, while only 24 per cent at the other hospitals were involuntary.

Nevertheless, any differences in numbers of involuntary patients would likely affect only slightly the type of advocacy which would be conducted by advocates. For example, advocacy work would be less "legal", since there would not be as much time spent on arranging Review Board Hearings or dealing with involuntary committals. Also, the percentage of cases addressing therapeutic and social issues (now 47 per cent within the PPAO) would likely be a larger percentage of the total within the private hospitals. However, much of the advocacy would likely remain the same, because advocates indicated they already spend a slight majority of their time on admitting wards. Advocates also noted that "therapeutic" issues are the most difficult, so that this experience would transfer relatively easily to the new settings.

These four hospitals have independent, community boards, which should increase their accountability to the community. In Bradley's comprehensive review of advocacy programs in the United States, this did not emerge as a factor which influenced either the need for, or quality of, an advocacy program (Bradley et al., 1982). Also, hospital boards are generally quite distant from the day-to-day operations of the hospital.

We have noted from key informants at these other hospitals that two of the facilities are in the process of "planning" advocacy programs, while a third has had a "patient representative" program for three years. All these programs are, or are expected to be, totally internal to the hospital. The "advocate" will report to, and be accountable to, someone in the hospital administrative hierarchy.

As discussed at length in Chapter IV, many staff define an important role for themselves as advocates. Following Milner's (1986) argument, it would seem that the advocacy initiatives at these private hospitals are an attempt by administration to build on staff's diffuse definition of advocacy, and to recognize the "rights" issue while at the same time building internal advocacy programs which will minimize conflict for staff.

Our data, however, indicated that the effectiveness of advocacy for patients was related to their perception that the advocate was "on their side." Similarly, in terms of both structure and effectiveness, our data have shown that advocates must be perceived to be independent and thus not be employed directly by the institution. While we respect the good will of staff in these institutions for initiating their own advocacy programs, our data and analysis point to the need for a more carefully constructed, independent advocacy initiative in these settings.

Expansion to Outpatients

Seven advocates, one CAB, a large number of people at the community meetings, and several submissions emphasized that the PPAO should expand its mandate to outpatients. Interestingly, advocates at four sites indicated they are already dealing with outpatient issues. We have some sense from staff data that institutional staff are ambivalent about advocates expanding their mandate in this fashion, but the advocates emphasized that important issues and concerns have been identified through this work. For some patients, continued involvement with the advocate once they are no longer in-patients increases the continuity and support of the advocacy.

Advocacy with outpatients clearly extends the advocate beyond the walls of the hospital, since many outpatients are dealing with difficult, complex community issues. It makes sense, therefore, to also examine advocacy for outpatients in light of our data on community advocacy. This will be discussed in a subsequent section.

Expansion to Other Institutional Settings

Table 18 shows that several respondents believed that the PPAO could benefit other psychiatric patients in a variety of institutional and community settings. We have already noted that transferring the major elements of the program to other psychiatric hospitals could occur fairly smoothly.

Expanding the PPAO to other institutional settings might be somewhat more problematic. In this section, we briefly discuss some of the issues of expansion and how key elements of the PPAO would need to be safeguarded in any process of expansion.

General Hospitals. There are strong arguments for expanding patient advocates to psychiatric wards of general hospitals. In recent years, the number of involuntary patients admitted to such wards has been increasing, indicating a need to carefully address the legal rights of these patients. Also, our key informants from general hospitals have noted that many general hospitals now have "patient representatives" who are available to respond to patient concerns. Some hospitals have noted concerns coming from the psychiatric wards, but we have no data to suggest that the number of concerns or complaints or their nature differs between the psychiatric wards and other wards of a general hospital.

There are also some difficulties in placing advocates in psychiatric wards of general hospitals. For one thing, advocacy in these wards to the exclusion of other wards of a hospital would tend to increase the stigmatization of psychiatric patients. Why, staff and the public would ask, do psychiatric patients need advocates any more than patients who are on a surgical ward? The reality is that probably all patients need a more consistent rights enforcement process, and it may be discriminating within an institutional context to respond only to one type of patient. As well, psychiatric patients are not always confined to one ward. Patients with a dual diagnosis, particularly psychogeriatric patients, are often found on other wards.

We believe that transferring or expanding the PPAO to psychiatric wards in general hospitals would be inappropriate unless it was part of a broad based advocacy program for the entire hospital. Should such proposals be considered in the future, it is important that the key elements identified during this study be observed in developing advocacy models for those institutions.

Homes for Special Care and Nursing Homes. One CAB and an administrator at a different hospital, along with submissions from the Ontario Association of Professional Social Workers, Registered Nurses Association of Ontario, and Concerned Friends emphasized the need to expand advocacy to Homes for Special Care and nursing homes. People argued that clients in these settings had an enormous number of needs which could be addressed by an effective advocacy program. While there can be little doubt that patients in these settings would benefit from a patient advocate, there are difficulties in expanding or transferring the PPAO to such settings.

First, nursing homes generally serve elderly people, a group with their own set of needs and concerns. One of our key elements, suggested in Chapter VI, was that advocates need to be somewhat specialized. It would seem more appropriate, therefore, that another small, coherent program be established to address the needs of older people in institutional settings. Granted, advocates in those settings would need to learn about psychiatric patients in much the same way that advocates in psychiatric hospitals are having to learn about the needs of older people.

Second, the submissions as well as interviews with key informants have confirmed that Homes for Special Care vary from community to community and have several problems which have been identified in a number of studies. More effective monitoring and advocacy systems are clearly needed as one of the methods of responding to these problems. Part of the difficulty of implementing such advocacy is that Homes for Special Care are made up of small and large nursing homes and residential facilities, including some boarding homes, all of which are, for the most part, privately operated. The clients in such settings also vary. Even though all residents are former patients of provincial psychiatric hospitals, some of the residents in Homes for Special Care have a dual diagnosis - they are developmentally handicapped and psychiatrically disabled.

Another finding of our study which might apply to both nursing homes and Homes for Special Care is the importance of conducting non-instructed advocacy in a sensitive manner. Much advocacy work in these settings would also require more proactive and systemic advocacy. Like psychogeriatric wards in the psychiatric hospitals, advocates in these settings would require specialized training, to learn how to encourage people to express themselves and, where appropriate, to utilize substitute decision-makers. Backup support would be vital for such advocates, and given the extensive need in this area, there may also be a need for a broad network of volunteer advocates. Finally, our data has suggested that more legalistic oriented advocates who prefer to take instructions would probably not be the most appropriate personnel for such settings.

Expansion To The Community

There was fairly widespread support for expanding the program to the community, among a minority of staff, 3 CABs, advocates (9 sites), community groups (6 sites), and former patients (5 sites).* In addition, approximately 25 per cent of the submissions that we received recommended the program's expansion to the community in one form or another. People noted that there is something illogical about ending advocacy at the institutional door when for many people their problems are augmented the moment they transfer into the community.

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* Former patients were present at only seven community meetings.

> *"We are increasingly addressing the social and political dimensions of our care-giving. There can be no doubt that advocates must get out into the community in order to adequately reach those who are in need of their services."*
>
> *(CAB)*

> *"I think there is an enormous need for advocacy beyond the institution. I think it is particularly apparent to us that for individuals who have had access to advocacy services when they are in-patients, it makes no sense at all for them to lose access to these services when they simply become an outpatient."*
>
> *(Community Service Agency)*

Some community agencies indicated that part of the advocates' expanded role should include more responsible planning with the patient around discharge from the hospital. Several service providers gave examples of people who were discharged, with the advocates' help, into the community before any proper supports had been arranged. Consequently, community agencies felt as if they were sometimes scrambling to pick up the pieces. As one public health nurse stated:

> *"Who is going to deal with that situation for the next two weeks? Is the advocate going to continue to be supportive of the person in the community? Is the advocate going to answer the distress calls and deal with that kind of decision that they helped reinforce? That is my problem..."*

Although our data point to a clear demand for expanded advocacy services (Table 18 summarizes people's comments), a few people introduced a note of caution into the discussion of community advocacy (Ministry of Health, two community groups, one advocate, and one CAB). These people were concerned that too many advocates in the community could actually perpetuate dependency rather than facilitate self-advocacy.

> *"I have some reservations about the professionalization of rights; there is a danger that we will become too dependent on advocates and be less effective in self-advocacy. The parallel is that we depend too much upon professionals for our help and we don't do enough self-help related to our own health."* *(CAB)*

On the other hand, the following quotations from patients indicated that many are feeling very lost in the community. Certainly if they do not need an advocate, they definitely need some process for learning the skills of self-advocacy.

> *"What do you do when you are on the outside and you're having problems and you don't want to go to the hospital? It's not psychological, it's financial. Who do you turn to? What are your rights? Do you have any rights?"*

> *"I am having a lot of trouble with Welfare right now. I don't even know if any patient advocate had been involved, or where do I ever find a patient advocate or whether I need a patient advocate or not, you know? Like I don't know of one. I am not in the hospital. So I don't know. Things go slow and I have no one to fight (for me.)"*

One member from the local branch of the CMHA, believed that the issue was actually one of determining where advocacy ends and case management begins.

> *"One of the examples I had given to me, which I think explains probably the confusion, and I would say that there is a lot of confusion about the difference between advocacy and case management and discharge planning and therapeutic intervention....there is no agreement where advocacy starts and case management begins and what the service process is. So, I think that is part of the confusion. There is a bigger problem than just trying to write some rules on role definition."*

One advocate stressed that the function of community advocates should not be that of simply coordinating other social agencies. The PPAO submission to the O'Sullivan Review stated quite clearly that there is a marked distinction between advocacy and case management. They recommended that:

> *"It would not be beneficial to include both advocacy and case management services in the mandate of advocacy models. In so doing, the potential conflict between self-determination and paternalism would be internalized in the advocacy service, and the advocacy role would be limited by the duality of the roles."*

TABLE 18

EXPANSION OF ADVOCACY TO THE COMMUNITY *

Why is Community Advocacy Needed?	• to provide a liaison for clients between the hospital and the community • to educate the public and agency service providers • to work on community placement • to chronicle needs • to address housing, employment, and public assistance problems • to push for more community based alternatives/resources • to assist former patients in accessing systems, agencies, Ministries, etc.
Who could Benefit from Community Advocacy?	• all people labelled psychiatrically disabled in: -community programs/community -general hospitals -homes for special care -nursing homes -outpatient programs • psychogeriatric and developmentally disabled people • all disadvantaged people
What should Community Advocacy Entail?	• train other community workers - Public Health Nurses/CMHA/volunteers • encourage self-advocacy • represent the client whenever needed • take pro-active rather than a reactive approach • influence policies and government initiatives
How should Community Advocacy Be Accomplished?	• expand the PPAO directly to other settings • create a separate program of the PPAO for the community • develop a provincial advocacy system for all disadvantaged people throughout Ontario

* *Based on views of advocates,CAB's, PPAO, PPAO Advisory Committee, Ministry, former patients,& community interviews & submissions.*

Our data analysis further clarifies the distinction between case management and advocacy. Advocates represent patients and might well "push" to get case management services organized. But their role is to not carry out the service or act as a broker for services. The problem, of course, is that there is seldom an identified "source" in the community who does case management, so advocates would need to be most careful that it does not fall on their shoulders by default.

Community Advocacy Options. How then should a community advocacy program be structured? People offered various suggestions (refer to Table 18), and cautions; from this data one thing seems clear, as one Ministry Official noted:

> *"What works in the hospital setting may not be a good model for the community."*

A number of community service providers commented on the fact that community advocacy would require a breadth of knowledge about mental health services and support systems in the community.

> *"I think one of the concerns with the advocate, it seems to me, is that there is sometimes a lack of knowledge of mental illness and also knowledge of the social services system at large. That is where I think a lot of the work needs to be done with the advocate. You cannot just see people in isolation."*

The question of how to expand advocacy to the community is one that is not easily resolved. As we discussed in a previous chapter on structure, certain political imperatives may necessitate the PPAO's re-organization under a provincial advocacy program. Recognizing that the smallness and flexibility of the PPAO is an asset, we have recommended that the PPAO retain its own autonomous program.

It seems that a consideration of community advocacy within the context of our study of institutional advocacy can take two forms. It can be *client-centred* in which advocates would work with psychiatric patients, wherever they happened to be whether in the institution, out-patients, or in the community. Alternatively the advocacy could be *location-centred*, in which advocates would work only in a specific setting, such as the hospital. Other advocates would 'pick up' the person when they became part of the community.

Our data do not strongly support one model, but careful analysis suggests both have benefits and limitations. The client-centred model clearly provides more continuity for the client. The location-centred model would increase the likelihood that advocates will be more readily available when needed. We might assume that client-centred advocates, because they know their clients in a variety of contexts, might resolve more difficult and entrenched problems. On the other hand, data presented in Chapter VI showed that advocates played a specialized role which required them to know the system in which they were working extremely well.

A few people recommended that community advocacy should not be part of the mandate of the advocates working within the institutions, but that a separate program be established under the umbrella of the PPAO. Elaborating upon this option, one advocate envisioned the two programs as separate but connected, thereby ensuring adequate follow-up and a team effort aimed at reducing the "revolving door" syndrome. This scenario would maintain some of the specialized components, but would demand a high degree of communication and collaboration between advocates. The concept of regional offices was suggested by one submission as a way to implement community advocacy.

Unfortunately, there is not a body of literature to assist us in determining which of the above models is likely to be most effective for patients. It seems valid, therefore, to suggest that any community advocacy models be phased in slowly and studied very carefully in the process.

One community in Ontario has experienced community advocacy for a decade and offers us an important case study.

Windsor Ombudsman Program. The Windsor Ombudsman Program was initiated in 1975 by the Canadian Mental Health Association of Windsor and Essex County. The Ombudsman Program is housed within CMHA but the Ombudsman spends time throughout the community (including two days per week in local hospitals), and the office has a high degree of independence. The Program started with a part-time Ombudsman, but the demand has been so great over the years, that it now has two full-time ombudsmen.

The mandate of the Windsor Program is:

- to advocate, inform, and advise patients of their rights under the Mental Health Act
- to investigate and seek to resolve complaints relating to mental health issues
- to provide information, referral, support, and guidance to individuals or their family/friends
- to offer assistance to professionals or community groups on issues pertaining to patients rights

The structure of the program includes an advocacy committee made up of consumers, service providers, and other community professionals.

The ombudsmen themselves have enormous energy and creativity in solving community problems. They strongly emphasized that the success of the program is based on cooperative problem-solving with community agencies. When supporting a patient to achieve his/ her rights, the ombudsmen collaborate, consult, link, and network with a variety of community members and services on behalf of the client. The Ombudsman's Office believed that one of the areas where they have had the most impact has been on promoting enhanced communication between patients and service providers. Not only do the ombudsmen provide client advocacy, but a strong element of the program involves outreach and education.

In the conclusion to an article which Winifred White, the senior ombudsman, wrote about the Windsor Ombudsman Program, she emphasized that:

> The ombudsman approach is to advocate for basic human rights...and above all, for commitment to a goal of ensuring that mental health services are available, accessible, efficient, affordable, acceptable, and accountable
>
> (Norton; 1985).

Many lessons can be gleaned from studying the Windsor Ombudsman Program. Given the need and demand, it would seem timely to consider how to expand advocacy for clients of mental health services to other communities.

Summary

In studying the possibility of expanding the PPAO, a number of issues have been raised. Our analysis suggests that there may be three kinds of expansion. The first involves direct expansion or enlargement of the PPAO to similar settings, such as private psychiatric hospitals or outpatient programs within the provincial hospitals. The second type of expansion would involve "adapting" the PPAO elements to other settings, which could possibly be coordinated by the PPAO. Finally, there is the idea of "transferring" certain elements of the PPAO, which would not entail any direct PPAO involvement in the implementation structure.

Our recommendations suggest ways that these various types of expansion could be accomplished.

RECOMMENDATIONS

1. The PPAO should be the focal point for planning and co-ordinating any expansion of advocacy services for psychiatric patients to ensure that key elements of the PPAO be safeguarded.

2. The mandate of the PPAO should be expanded to include out-patients, former patients with concerns related to the institution, and persons seeking the services of the institution.

3. The PPAO should be expanded to include the four other psychiatric hospitals in Ontario and a variety of administrative and implementation issues should be carefully studied prior to this expansion.

4. Any additional PPAO expansion should be "phased in" in a manner which is coherent with the development of any province-wide advocacy structure, and these expansions should include:

    - development of pilot projects which would adapt and modify the PPAO model to other Ministry of Health facilities which service psychiatric patients, including Homes for Special Care, and Approved Boarding Homes.

    - a comprehensive study to consider how to adapt and modify the key elements of the PPAO model to a community advocacy program.

REFERENCES

Advocacy Resource Centre for the Handicapped, Submission to the Honourable Larry Grossman, 1982 (December).

Advocacy Resource Centre for the Handicapped, Submission to the PPAO Evaluation Committee, 1987 (March 25).

Anthony, W. A., Cohen. M. Farkas. M. A Psychiatric rehabilitation treatment program: can I recognize one if I see one?. *Community Mental Health Journal,* 1982, 18:2, pp. 83-96.

Appelbaum, P. S. The rising tide of patients rights advocacy. *Hospital & Community Psychiatry,* 1986, 37:1, pp. 9-10.

Appelbaum, P. S. & Hoge. S. K. The right to refuse treatment: what the research reveals. *Behavioural Sciences & The Law,* 1986, 4:3, pp. 279-292.

Appelbaum, P.S. & Roth. L. H. Patients who refuse treatment in medical hospitals. *Journal of the American Medical Association* . 1983, 25 o, pp. 1296-1301.

Armstrong, B. A question of abuse: where staff and patient rights collide. *Hospital and Community Psychiatry,* 1979, 3:5. pp. 348-351.

Atkinson, S., Madill, M.F., Solberg, D., Turner, T. Mental health advocacy: paradigm or panacea? *Canada's Mental Health,* 1985, 33:3, pp. 3-7.

Baucom, L. & Bensberg, G. (eds.). *Advocacy Systems for Persons with Developmental Disabilities: Context, Components and Resources,* Lublock, Texas: Research and Training Centre in Mental Retardation, 1977.

Bercovici, S. Qualitative methods and cultural perspectives in the study of deinstitutionalization. In :Bruininks. R.H., Meyers. C.H., Sigford, B.B., Lakin, K.C.(Eds.) *Deinstitutionalization and Community Adjustment of Mentally Retarded People.* Washington, D.C.: American Association on Mental Deficiency, 1981.

Biklen, D. *Let Our Children Go: An Organizing Manual for Advocates and Parents,* Syracuse: Human Policy Press, 1974.

Blatt, B. *Exodus from Pandemonium: Human Abuse and the Reformation of Public Policy*. Boston: Allyn and Bacon, 1970.

Bloom, H. & Asher, J. *Patient Rights and Patient Advocacy: Issues and Evidence*, New York: Human Science Press, 1982.

Bogden, R. & Taylor, S.J. *Introduction to Qualitative Research Method: A Phenomenological Approach to the Social Sciences*, New York: John Wiley & Sons, 1975.

Book, H. L. Some psychodynamics of non-compliance. *Canadian Journal of Psychiatry*, 1987, 32, pp. 115-117.

Bowles, R. T. *Social Impact Assessment in Small Communities*. Toronto: Buttersworth, 1981.

Bradley, V. & Murphy, J. *Evaluation of Models of Advocacy Programs for the Mentally Ill and Developmentally Disabled: Final Report*, Vol. 1, *Summary of Findings & Policy Implications*. Maryland: National Institute of Mental Health, 1980.

Bradley, V. et al. *Exploration of Advocacy Models for the Mentally Disabled*, NIMH Grant 18-MH 36478-01, 1978.

Bradley, V. et al, *Further Exploration of Advocacy Models for the Mentally Disabled*, NIMH grant -MH36478-01, 1982.

Campbell, D. & Stanley, I. *Experimental and Quasi-experimental Designs for Research*. Chicago: Rand, McNally & Company, 1967.

Canadian Mental Health Association. *Community Reinvestment: Balancing the Use of Resources in Support of People with Mental Disabilities*, 1987.

Carpenter, W., McGlashan, T. & Strauss, J. The treatment of acute schizophrenia without drugs: an investigation of some current assumptions. *American Journal of Psychiatry* 1977, 134:1, , pp. 14-20.

Chamberlin, J. *On Our Own*, Toronto: McGraw-Hill Book Company, 1978.

Chandrasena, R. & Smith, S. Regional review boards of Ontario: medico-legal review. *Canadian Journal of Psychiatry* , 1986, 31, pp. 643-647.

Concerned Friends of Ontario. Submission to the PPAO. 1987 (January. 23).

Coye. J. & Clifford. D. A one-year report on rights violations under Michigans' new protection system. *Hospital & Community Psychiatry*. 1978: 29:8. pp. 528-533.

DeJong. G . Independent living: from social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*. 1979. 60. pp.435-446.

Dejowski. E. Feedback: A patient advocate's view of informed consent: Neither a document nor a noun. *Hospital & Community Psychiatry*. 1981. 32:3. pp. 206-207.

Dimirsky. M. System needs for the rehabilitative treatment of the revolving door population. *Canadian Journal of Community Mental Health*. 1982. 1:2. pp. 64-75.

Eth. S.. Levine. N.. & Lyon-Levine. M. Ethical conflicts at the interface of advocacy and psychiatry. *The Hospital & Community Psychiatry*. 1984. 35:7. pp. 665-666.

Freddolino. P.. P. & Applebaum. P.. S. Rights protection and advocacy: The need to do more with less. *Hospital & Community Psychiatry*. 1984. 35. pp. 319-320.

Glaser. B. & Strauss. A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine. 1967.

Goffman. E. *Asylums*. Garden City: Anchor Doubleday. 1961.

Government of Ontario. *Mental Health Act*. Queen's Printer. 1985.

Hassenfeld. I. & Grumet . B. A study on the right to refuse treatment. *Bulletin of American Academy of Psychiatric Law*. 1984. 12:1. pp. 65-74.

Herman. N. *Crazies in the Community: An Ethnographic Analysis of the Post-hospital Lives of Chronic Ex-mental Patients*. Paper presented at Qualitative Research Conference. University of Waterloo. May. 1985.

Heseltine. G.F. *Blue Print for Change: The Next Ten years*. Toronto: Ontario Ministry of Health. 1985.

Hilliard. J. D. & Gutheil. T. Comments on dealing with 'irresponsible' advocates. *Hospital & Community Psychiatry*. 1981. 32:11. pp. 803-804.

Hoaken, P.C.S. Psychiatry, civil liberty, and involuntary treatment. *Canadian Journal of Psychiatry*, 1986, 31:3, pp.222-226.

Hucker, S. et al. *Oak Ridge: A Review and an Alternative*. Ontario Ministry of Health, 1984.

Hutchison, P., Lord, J. Savage, H., & Schnarr, A. *Listening: to People who Have Directly Experienced the Mental Health System*. Toronto: Canadian Mental Health Association, 1985.

Hutchison, P. , Lord, J. & Osborne-Way, L. *Participating: With People Who Have Directly Experienced the Mental Health System*. Toronto: Canadian Mental Health Association, 1986.

Kopolow, L., & Bloom, H. (Eds.) *Mental Health Advocacy: An Emerging Force in Consumer Rights*. Maryland: U.S. Department of Health Education and Welfare, 1977.

Korabik, K. The use of theory-relevant goals as a means of enhancing utilization. *Canadian Journal of Community Mental Health*. 1985, 4:2, pp.35-43.

Lamb, H. R. Securing patients' rights- responsibly. *Hospital & Community Psychiatry*, 1981, 32:6, pp. 393-397.

Laves, & Cohen. A preliminary investigation into the knowledge and attitude toward the legal rights of mental patients. *Journal of Psychology and Law*, 1973, p. 49.

Lord, J. Advocacy for Change. *Journal of Leisurability*, 1981, 8:1, pp. 4-12.

Miles, M. & Huberman., M. *Qualitative Data Analysis: A Source Book of New Methods*, Beverly Hills: Sage Publications, 1984.

Miller, R. D. & Maier, G. J. Factors affecting the decision to prosecute mental patients for criminal behaviour. *Hospital and Community Psychiatry*. 1987, 38:1, pp. 50-55.

Milner, N. The symbols and meanings of advocacy. *International Journal of Law and Psychiatry*, 1986, 8, pp. 17-23.

Mowbray, C., Freddolino, P., Rhodes, G., & Greenfield, A. Evaluation of a patients rights protection system: public policy implications. *Administration in Mental Health*, 1985, 12:4, pp. 264-283.

implications. _Administration in Mental Health_, 1985, 12:4, pp. 264-283.

Murphy, S. Vocational rehabilitation counselling and advocacy: an analysis of dissonant concepts. _Rehabilitation Literature_, 1980, 41:1 & 2, pp.3-10.

Netting, E., & Hinds, H., N. Volunteer advocates in long-term care: Local implementation of a federal mandate. _The Gerontologist_, 1984, 24:1, pp. 13-15.

News & Notes: Michigan Mental Health Department. Trying to eliminate abuse in mental retardation facilities. _Hospital & Community Psychiatry_, 1978, 29:9, pp. 621-624.

Norton, W. Ombudsman in Mental Health. _Canada's Mental Health_, 1985, 33:3, pp. 17-18.

Patton, M. Q. _Utilization Focused Evaluation_. Beverly Hills, California: Sage Publications Inc., 1978.

Patton, M. Q. _Qualitative Evaluation Methods_. Beverly Hills, California: Sage Publications Inc., 1980.

Pettifor, J. Patients' rights, professional ethics, and situation dilemmas in mental health services. _Canada's Mental Health_, 1985, 33:3, pp.20-23.

Phoenix Rising. Special Issue on the Charter of Rights and Freedom and The Psychiatric System, 1985, 5:2 & 3.

Psychiatric Patient Advocate Office. _First Report_, 1984.

Psychiatric Patient Advocate Office. Policy Guidelines for non-patient initiated advocates, Revised September 1985.

Psychiatric Patient Advocate Office, Submission to the Review of Vulnerable Adults in Ontario, O'Sullivan Review, April 14, 1987.

Psychiatric Patient Advocate Office, Advocates submission to the PPAO Evaluation Committee "Whither We Go", 1986.

Quilitch B., & Christensen, K. Using an ombudsman and a rights committee to handle client complaints. _Hospital & Community Psychiatry_, 1981, 32:2, pp. 127-129.

Rutman, L. *Evaluation Research Methods: A Basic Guide*. 2nd Ed. Beverly Hills: Sage Publications Inc., 1984.

Savage, H. Human Rights for handicapped persons: Toward a multi-track approach, *Journal of Leisurability*, 1980, 7:4, pp. 5-11.

Schafer, A. The right of institutionalized psychiatric patients to refuse treatment. *Canada's Mental Health*, 1985, 33, pp. 12-16.

Scott, E. The mental health advocacy service: a legal perspective. In Kopolow L. and H. Bloom (Eds.). *Mental Health Advocacy: An Emerging Force in Consumers' Rights*. Maryland: U.S. Department of Health, Education, and Welfare, pp. 47-48, 1977.

Shannon, P. Coercion and compulsory hospitalization: Some patients attitudes. *Medical Journal of Australia*, 1976, 2, pp. 798-800.

Special Committee on the Disabled and the handicapped. *Obstacles*, Ottawa: Government of Canada, 1981.

Stahler, G., J. & William Tash (eds.). *Innovative Approaches to Mental Health Evaluation*, New York: Academic Press, 1982.

Stone, A. A. The myths of advocacy. *Hospital and Community Psychiatry*, 1979, 30:12, pp. 819-822.

Talbott, J. A. The Death of Asylum. *A Critical Study of State Hospital Management, Services and Care*, New York: Grune & Stratton, 1978.

Taylor, D. Child advocacy within state government. In Paul, J., D. Stedman & G. Neufeld (eds.). *Deinstitutionalization: Program and Policy Development*, Syracuse, New York: Syracuse University Press,1977.

Toews, J., Guebalym N., Leckie, A. & Harper, D. Patients' attitudes at the time of their Commitment. *Canadian Journal of Psychiatry*, 1984. 29, pp. 590-595.

Touche Ross & Partners. *A Review of the Homes for Special Care Program: For the Mental Health Division* , Ontario Ministry of Health, Toronto, 1984.

VanNess, S., & Perlin, M. Mental health advocacy. The New Jersey experience. In Kopolow L., and Bloom, H., (eds). Mental Health Advocacy: An Emerging Force in Consumers Rights, Maryland: U.S. Department of Health, Education and Welfare, 1977.

VanPutten, T. Subjective response as a predictor of outcome in pharmacotherapy: the consumer has a point. Arch General Psychiatry, 1978, 35, pp. 477-480.

Vrooman, P. C. Does legal advocacy and redistribution by the courts produce better social policies for the mentally handicapped? International Journal of Law & Psychiatry, 1980, 3, p. 89-96.

Wald, P. & Friedman, P. R. The politics of mental health advocacy in the United States. International Journal of Law and Psychiatry, 1978, pp. 137-152.

Walker, K. Advocacy: its principles and practice. Unpublished paper, 1985.

Weiss, C.H. Utilization of evaluation: toward comparative study. In C.H. Weiss (Ed.). Evaluation and Action Programs; Readings in Social Action and Education. Boston: Allyn and Bacon, 1972.

Weiss, R. S. & Rein M. The evaluation of broad aim programs: experimental design, its difficulties, and an alternative. Administrative Science Quarterly, 1972, 15, pp.97-109.

Willetts, R. Advocacy and the mentally ill. Social Work, 1980: September, pp. 372-377.

Willetts, R. Models of Mental Health Advocacy: A Comparative Analysis. Ann Arbor, Michigan: UMI Dissertation Information Service, 1981.

Wilson, J. et al. Advocacy for the mentally disable. In L. Kopolow and Bloom, H. (eds), Mental Health advocacy: An Emerging Force in Consumers Rights, Maryland: U.S. Department of Health, Education, and Welfare, 1977.

Wiseman, J. P. Stations of the Lost. Engleweed Cliffs, N.J.: Prentice-Hall, Inc., 1970.

Wolfensberger, W. A multi-component advocacy/protection schema. In Law and Mental Retardation: A Monograph Series. Toronto: Canadian Association for the Mentally Retarded, 1977.

Wolfensberger, W. & S. Thomas. Passing: Program Analysis of Service Systems' Implementation of Normalization Goals, (2nd ed.). Toronto: National Institute of Mental Retardation, 1983.

Wolfensberger, W. & Zauha H. (eds.) Citizen Advocacy and Protective Services for the Impaired and Handicapped. Downsview, Ont.: National Institute on Mental Retardation, 1973.

Ziegenfuss, J. T. The varied role of patients rights representatives in an organizational grievance program. Administration in Social Work, 1984, 8: 2, pp. 59-67.

Ziegenfuss, J. T. Conflict between patients' rights and needs: An organizational systems problem. Hospital & Community Psychiatry, 1986, 37:11, pp. 1086-1088.

Appendix A

Provincial Psychiatric Hospital Catchment Areas

HOSPITAL	CATCHMENT POPULATION	COUNTIES INCLUDED IN CATCHMENT
BROCKVILLE	809, 700	Leeds-Grenville, Ottawa-Carleton, Prescott-Russell, Stormont-Dundas-Glengarry.
HAMILTON*	1,159,900	Brant, Haldimand, Halton, Hamilton-Wentworth, Niagara.
KINGSTON*	592, 500	Frontenac, Haliburton, Hastings, Lanark, Lennox-Addington, Northumberland, Peterborough, Prince Edward Island, Renfrew.
LAKEHEAD	237,800	Kenora, Rainy River, Thunder Bay.
LONDON*	978,900	Huron, Middlesex, Oxford, Perth, Waterloo, Wellington.
NORTH BAY	590,700	Algoma, Cochrane, Manitoulin, Nipissing, Parry Sound, Sudbury, Timiskaming.
PENETANG-GUISHENE	440,500	Bruce, Dufferin, Grey, Muskoka, Simcoe.
QUEEN STREET*	1,912,100	Western Metro Toronto, Peel.
ST. THOMAS	702,400	Elgin, Essex, Kent, Lambton, Norfolk.
WHITBY	1,393,800	Durham, East Metro Toronto, Victoria, York.

Hospitals are located in underlined counties.

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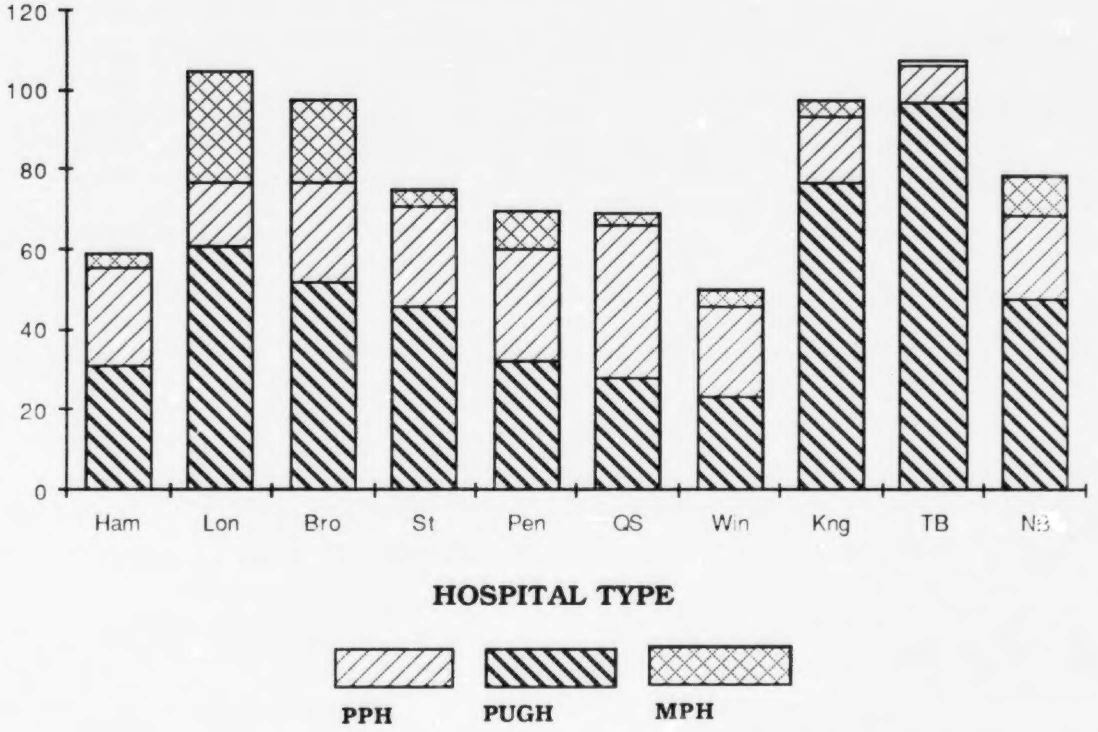
*Hospitals in same city as medical school.

CENSUS RATES: ONTARIO 1985/6

By PPH Catchment Area



Patients on file (on Census) per 100,000 population in:

Provincial Psychiatric Hospitals (PPH)

Psychiatric Units in General Hospitals (PUGH)

Miscellaneous Psychiatric Hospitals (MPH) --

includes Clarke Institute, Toronto METFORS, Toronto Baycrest, Royal Ottawa Hospital, Homewood, Subbury-Algoma Hospital, London Victoria Hospital.

Source: Ontario Ministry of Health

Information Systems Division
Information Resources and Services BranchTable OSADM49 1985/6

APPENDIX B

HOSPITAL ________________ DATE ____________

ADVOCATE ________________

Case No. type (a, b, c, d)	Age Sex	Duration of Latest Hospital-ization	Prior Hospital-ization	Type of Advocacy	Instructions Fulfilled	Unit	Status Admission	Current Status
145a	45 F	7 months	yes	legal	fulfilled	geri	vol	vol

Appendix C

Knowledge Survey

Below you will see seven statements regarding patients' rights. Some are true and some are false. We would like to get an idea of your knowledge of legal rights. Please put a circle around either the T (True) or F (false) to each statement.

		% Correct	
		Patient	Staff
1.	When a person is admitted, the doctor decides if the person can handle his/her own financial affairs. TRUE	66.3	80.1
2.	Both voluntary and involuntary patients can discharge themselves from hospital whenever they want. FALSE	78.6	97.5
3.	All patients can have a copy of their clinical record if they request it. FALSE	30.3	45.3
4.	Patients have the right to apply to the Regional Review Board to have doctor's decision to involuntarily commit the person reviewed. TRUE	86.5	97.5
5.	A doctor can keep renewing a person's certificate of involuntary admission indefinitely, as long as the required criteria are met. TRUE	77.5	81.9
6.	If the person is a voluntary patient, but meets the criteria for an involuntary patient, the doctor can sign a Certificate of Involuntary Admission. TRUE	84.2	78.8
7.	No one can interfere with mail sent to and from a patient. FALSE	21.3	31.0

Appendix D

Local Systemic Case Studies

Local Systemic Case #1

Issue: Workers' Compensation

Initiating: One patient who sustained an injury at work inquired about getting Workers' Compensation.

Developing a Strategy: Advocate inquires from hospital staff about WCB coverage. Hospital staff opinion is that patient activity is "therapy", not "work." Advocate consults Head Office legal counsel and PPAO Coordinator. Coordinator suggests this is a far reaching issue and a test case would be appropriate.

Activities: Patient instructs advocate to submit a compensation claim. Other patients express interest. Advocate suggests article in patient newsletter.

Outcomes: WCB proposes to compensate the patient. The hospital objects and asks WCB to reconsider the case.

Activities: PPAO Coordinator summarizes issue in letter to Chairman of WCB. Patient instructs advocate to involve legal counsel from ARCH.

Outcome: Letter from WCB Chairman to PPAO Coordinator confirming that the client was a "worker" under their act and that all patients employed in government psychiatric workshops, as well as sheltered workshops in other settings, are eligible for workers' compensation benefits.

Commentary: In this case, a single patient inquiry resulted in the involvement of Head Office and outside legal counsel and developed into a province-wide issue extending beyond the psychiatric hospitals. It resulted in both direct benefits to clients and in clarification of WCB policy for all sheltered workshops in the province.

Illustrates: Advocate role in developing hospital policy

Local Systemic Case #2

Issue: 'Pyjamas' - withholding of clothes for punishment and control of patients.

Initiating: Six individual cases documented by advocate, along with an analysis, in letter to hospital administrator.

Developing a Strategy: Copy of hospital policy obtained. Administrator takes issue to Professional Advisory Committee. Advocate monitors case and keeps it alive by meeting with senior clinical staff and continual presentation of individual cases.

Activities: Advocate meets with senior clinical staff and administrator. Follows up with memo and further client cases.

Outcome: Professional Advisory Committee issues new draft policy. Advocate comments on draft. Two of three changes proposed by advocate are included in final draft.

Commentary: In this case, the advocate highlighted a repetitive patient issue. Although never a member of the hospital committee dealing with the issue, the advocate did meet with the key actors and received and reviewed all working papers. The advocate kept the issue alive by continuing to send documented cases forward to the policy committee.

The current advocate notes, however, that the office still gets complaints about clothing withheld and that the program has no practical way of monitoring the issue.

This case illustrates the value of advocates working with administration to resolve policy.

We also note that in several cases, advocates with special expertise have been invited to sit on hospital policy committees and participate directly in policy development.

Local Systemic Case #3

Issue: Developing a Patient Government

Initiating: One patient approached advocate on behalf of his workshop group regarding pay increase.

Developing A Strategy: Exploration. Advocate gets information from Head Nurse. Finds out who makes decisions on wages and which budget is involved.

Activities: Advocate meets with group of patients. Issue applies to all workshops. Advocate suggests a petition. Patients vote to have a petition. Patient suggests letter to government. Advocate helps draft letter and patient group approves. Advocate suggests using patient newsletter and local newspapers. Patients begin talking about patient government/self-dvocacy.

Fortuitous Event. Advocate hears Minister of Health is visiting hospital. Patient group instructs advocate to arrange meeting of patients with Minister

Outcome: Minister of Health grants an immediate 5 cent per hour wage increase.

During this process, a number of other patient issues are raised. While celebrating their victory the advocate suggests that the patients have worked together well--why don't they form a patient government and work on the other issues? The patient group calls an All Patients Meeting and a slate of officers is elected.

The patient government has now operated for two years, using the patient newsletter as a major vehicle for its activities. The patient government has tackled a number of new issues. The advocate serves as the executive assistant to the patient government, takes minutes at meetings, researches issues, and provides advice regarding strategies.

Commentary: In this case the initial patient complaint was resolved quickly, primarily because of a fortuitous event - the visit of the Minister of Health.

However, the advocate built on the cooperative, democratic style of the patient group involved to develop a more permanent forum for patient self-advocacy.

Local Systemic Case #4

Issue: The use of restraints on patients travelling on aircraft in the north.

Initiating: One patient complained about strait-jacket restraints used when on aircraft.

Developing a Strategy: Advocate seeks information on restraint policies from airlines and hospitals in the north. Checks with two other advocates. One says it is not an issue; the other says it is a legal issue. Advocate tends to agree with northern medical staff that it is due to ignorance in the absence of any clear policies.

Activities: Advocate seeks support of senior clinical staff in northern hospitals for in-service program. Enlists support of medical director of psychiatric hospital. Develops and suggests alternatives to strait-jackets with nursing director in northern hospital.

Outcomes: Educational program planned for northern clinical staff, to be conducted by the advocate and medical director of the psychiatric hospital. New policy in place in northern hospital which gives patients a choice of restraints and if a strait-jacket is chosen, it is removed when the plane hits the ground. Monitoring by the advocate of patients arriving by air indicates the policy is working.

Commentary: This case illustrates how one patient's complaint led to significant changes in patients' rights, policies, and procedures; the education of clinical staff; and a new relationship between the psychiatric hospital and other hospitals in the area. The changes were accomplished entirely by careful research, creative ideas, and reasoned discussion. As the advocate said, "you can do a lot just by asking questions."

Local Systemic Case #5

Issue: Housing.

Initiating: Social worker obtained housing for two patients. Later, both patients were turned down because they were patients. The social worker was reassigned and asked advocate to oversee the case. Patients gave up, but advocate continued with the issue of systemic discrimination.

Developing a Strategy: A subcommittee of a housing Board votes in favour of a policy that no forensic patients be accepted and suggests they be housed instead by the Ministry of Corrections. The subcommittee is made up of hospital staff who have volunteered to work with the housing project.

An educational approach has already been pursued by the social worker. The advocate determines that the medical director of the hospital and other hospital physicians are supportive of patients having rights to the housing program.

The advocate is active on a volunteer basis on housing questions in the community. The advocate reviews the issue as systemic discrimination against forensic patients.

Outcome: The issue is still pending.

Commentary: Developing a strategy is the problem in this non-instructed, systemic case. Questions include: Is this issue in the advocate's mandate? It does involve inpatients, but it is a community issue. How much time can the advocate spend on the issue? Is it a provincial issue: It involves a housing program funded by another branch of the Ministry of Health; the Ministry of Corrections might also be involved.

Options include: contacting other advocates with forensic units and documenting cases; finding one client who will pursue it; initiating a legal test case under the Charter; involving Head Office in challenging another Ministry of Health program.

This case illustrates how inpatient issues that cross the boundaries of the hospital became complicated for the advocates, and how an issue can be perceived as local or provincial. It also illustrates the need for a systemic policy coordinator in Head Office to advise and assist the advocate with complicated decisions.

Appendix E

PROVINCIAL SYSTEMIC CASE STUDIES

Provincial Systemic Case #1

Issue: Comfort allowance. Persons receiving disability pension prior to admission to a provincial psychiatric hospital have those benefits terminated on admission. Termination does not occur if a person is admitted to a general hospital psychiatric unit.

Initiating: One advocate referred one patient complaint to the Ombudsman's office. The case was analyzed at case conference and it was agreed that it was a general problem affecting patients in all hospitals.

Developing a Strategy: The Coordinator immediately seeks collaboration with the Ombudsman who replies that he now has several other cases on hand and agrees that it is a larger issue.

The Coordinator seeks information regarding the policy from the Ministry of Community and Social Services, which administers the benefit, and learns that benefits are terminated because "all patient needs are met by the facility".

The PPAO strategy becomes one of assembling documentation demonstrating that all needs are not met by the facility.

Activities: The Coordinator requests that each advocate assembles information on hospital policies and procedures for meeting the personal needs of patients. These vary considerably from one hospital to another. Detailed information is received from every hospital.

The Assistant Deputy Minister also seeks information from each hospital by questionnaire, but abandons this method because of non-response and incompatible information.

The Coordinator and the Ombudsman have frequent, regular communication about the issue. The Coordinator forwards the advocates' research to the Ombudsman. The Ombudsman concludes his investigation and informs the PPAO that he is recommending that all psychiatric patients receive the comfort allowance. The Ministry of Community and Social Services consults with the Ministry of Health.

Information is received from ARCH, which was involved in two cases from patients demanding comfort allowance, indicating that the Ministry of Health has recommended to the provincial cabinet that all patients in psychiatric hospitals and Homes for Special Care receive the comfort allowance.

Advocates begin pressing Head Office for a conclusion to this issue.

Outcomes: The PPAO continues to monitor the case, but no decision has yet been made by the government. Advocates continue to refer cases to the Ombudsman.

Commentary: This case was initiated by an advocate referral to the Ombudsman and was pursued in direct cooperation with the Ombudsman's office. The major role of the PPAO was to research information in each hospital. This information required on-site research as the Ministry of Health was unable to obtain it through a questionnaire.

This on-site research plus the continuing flow of referrals of individual cases to the Ombudsman considerably strengthened the Ombudsman's case. In this situation, the advocates are pressing Head Office and forwarding more cases to keep the issue alive until it is resolved by government.

Provincial Systemic Case #2

Issue: Voting rights: This issue was addressed to ensure that appropriate changes are made to municipal, provincial, and federal election acts to permit psychiatric patients to vote in elections as guaranteed by the new Federal Charter of Rights and Freedoms.

Initiating: Several patients' rights groups reviewing the new Charter sought to establish the rights guaranteed by the Charter for psychiatric patients. CMHA, ARCH, and the PPAO worked together on achieving voting rights for all levels of elections.

Activities and Outcomes: The PPAO and other groups make submissions to the Members' Services Committee of the Provincial Legislature. The Committee immediately votes to amend the Provincial Elections Act to enfranchise psychiatric patients, making Ontario the first province where psychiatric patients are fully enfranchised.

Three months later, a provincial election is called. The PPAO works with other community groups to ensure the enumeration and voting procedures inside institutions resembled normal community voting practices.

The Ministry of Health issues guidelines for voting to hospital administrators. The PPAO issues instructions to advocates for the monitoring of election procedures. The PPAO produces a summary report on enumeration, voting day activities, patient education, political activity and patient complaints. They complete an analysis of hospital polls demonstrating that patients' voting patterns parallel those in the local riding. This report, and its recommendations, is widely distributed to interested agencies and government bodies.

Municipal voting rights : Municipal voting rights were more difficult to secure. The PPAO again participated in a campaign led by the CMHA (Ontario Division), and ARCH.

In response to a request from the Ministry of Municipal Affairs and housing, each advocate determines the municipal location of each hospital. The PPAO Head Office arranges for a resolution, endorsed by the City of Toronto Medical Officer of Health and Board of Health, to put before the Association of Municipalities of Ontario. The Coordinator participates in media coverage of the issue and advocates discuss the issue with MPP's and local Aldermen.

Although the Association fails to endorse the resolution, amendments to the Municipal Election Act, giving all psychiatric patients the right to vote, receive Royal Assent just two weeks before municipal elections are held throughout the province.

Once again, advocates observe and report on the voting process and forward the note from their local poll to Head Office for analysis of voting patterns.

Federal Voting Rights: A number of groups including ARCH, CMHA (National), the Status of Disabled Persons (federal), and the Ministry of Health are working on this issue at this point in time.

The PPAO resolves the issue and presents a Brief to Privileges and Elections (federal). PPAO research was also used by CMHA. All groups lobby individual MPP's.

The federal White Paper on Election Law Reform (June, 1986) proposes that there be no polling stations in psychiatric hospitals and no proxy vote allowed. The recommendations are opposed by all groups involved, including the PPAO. There has been no further activity on this issue since October, 1986.

Commentary: In this case, the PPAO acted in concert with a number of other groups, including the Ministry of Health, to secure voting rights pursuant to the federal Charter of Rights and Freedoms.

The unique contribution of the PPAO depended upon the presence of advocates in each hospital. From this vantage point, they were able to monitor the voting process and document election results. Head Office was able to assemble this data into a report demonstrating that enfranchisement did not skew election results and recommending some improvements to the process in future.

Provincial Systemic Case #3

Issue: Transfers of patients from psychiatric hospitals to maximum security, Penetang.

Initiating: One advocate noted that involuntary patients from psychiatric hospitals areas were being transferred to maximum security, Penetang. The advocate believed that some of these transfers were inappropriate and unnecessary, and provided documentation of sample cases to the PPAO Coordinator.

Deciding on a Strategy: After informal discussions between the Coordinator and advocates involved in the documented cases, one advocate volunteers to draft a strategy for consideration. A case conference confirms that this is a problem affecting many hospitals and that the issues require Head Office involvement with the Ministry of Health regarding policies. The following strategy is approved by advocates and recommended at the case conference:

A) Collect cases on inappropriate transfers - documentation to be sent to Head Office.

B) Collect information on manner of arrangements made for transfer - documentation to be sent to Head Office.

C) All Advocates to request copies of transfers from Administration.

D) Letter to Administrator of Mental Health Branch to to clarify transfer procedure - by Head Office.

E) Standardization of transfer criteria - Head Office.

F) Applicability of prison case to mental patients - ie., Charter cases on detention without due process-Head Office.

G) Examine therapeutic safeguards, and opinions, re: Secure/ Forensic/Medium Secure Treatment Units/combines L.G.W.'s Psychiatric involuntary/remands - Head Office.

Activities: The Coordinator instructs all advocates, by memo, to obtain information on all transfers to Penetang: to visit each patient where transfer was indicated on the daily report; if the patient was objecting to transfer, to get instructions from the patient; to advise Head Office. A summary of legal and policy matters prepared by legal counsel is appended.

The Coordinator writes to the Assistant Deputy Minister informing him of the issue and requesting clarification of hospital and Ministry policies and procedures. No reply is in file.

Some months later, two advocates write to the Director of Ministry of Health Operations reviewing Ministry and hospital policies and procedures and raising further questions and issues.

Meanwhile, advocates are submitting case after case to Head Office. Cases come in for a period of more than one year during which there appears to be little further activity on the issue.

Outcomes: The issue is largely unresolved. The medical director at Oak Ridge is personally reviewing the medical status of every civilly committed patient at Oak Ridge. The Ministry of Health has agreed to open forensic units in most hospitals so they can manage their own patients and avoid transferring them to a maximum security unit elsewhere. The issue of due process for patients prior to transfer has not been dealt with yet.

Commentary: This is one of the few systemic issues where the PPAO has acted alone. It concerns events entirely within the hospital system.

In this case, individual advocates raised the issue, drafted a strategic plan, and collected careful documentation. Legal counsel prepared a legal and policy background paper. The Coordinator and a sub-committee of advocates communicated with Ministry officials. Only a partial response has been made to the issues raised.

This case seems to be on hold for a number of reasons: the lengthy period when there was an acting Coordinator and the PPAO was pressed to deal with legislative issues, the provincial review of Oak Ridge, and subsequent philosophical and personnel changes at that facility. In part, the issue became "soft" because the PPAO did not have Head Office personnel dedicated to systemic work and because the PPAO became distracted by the demands of legislative reform. In part, it may be appropriate to wait and see how other, ongoing processes work out. The danger is that there is no apparent mechanism in place to ensure watchful monitoring of the issue and to identify the opportune time for further activity by the program.